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AspecTS

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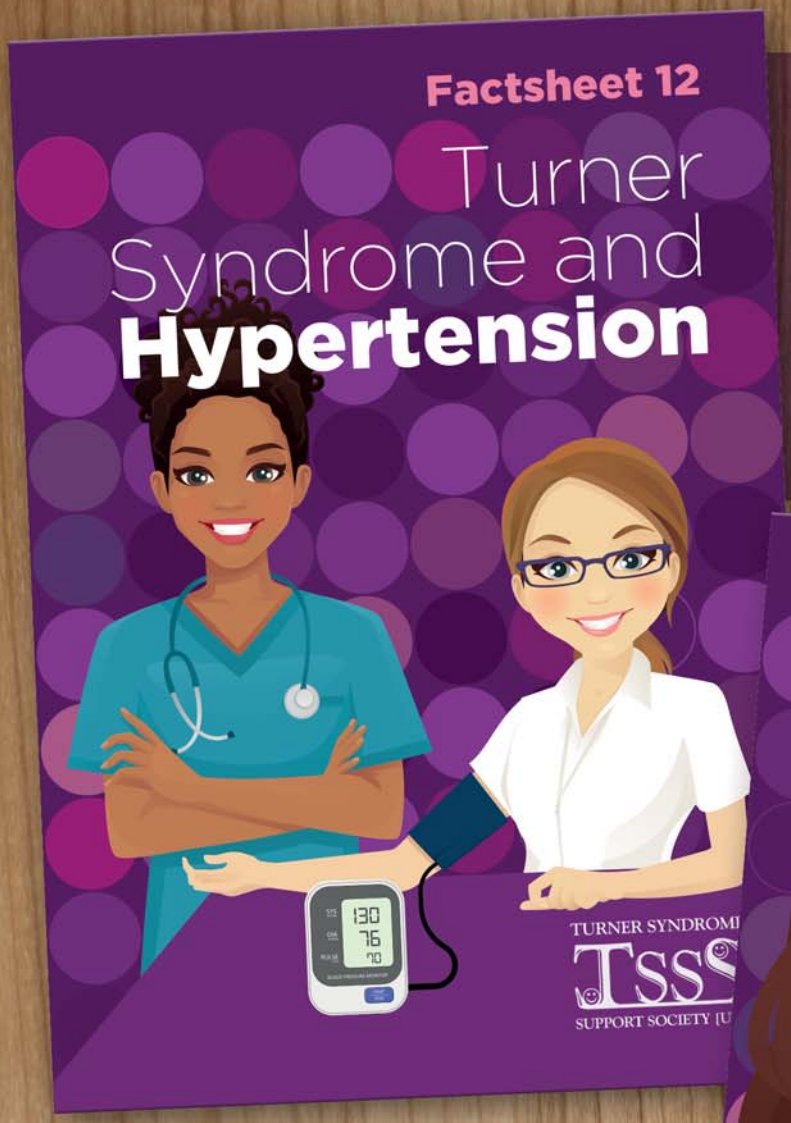

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TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

TURNER SYNDROME SUPPORT SOCIETY NEWSLETTER

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Editor's Message

Welcome to the Spring edition of AspecTS.

It has been a difficult 12 months for many people, some more than others, but at last we are seeing the light at the end of the tunnel and, hopefully, soon we may be able to start meeting friends and family in person.

We have all had Covid-19 but, thankfully, a relatively mild dose and Mag and I have now had our first vaccination and so feel a little safer. Hopefully, all who are able to, will get their vaccines soon.

There are many interesting articles from our members in this latest edition, many thanks to all contributors and please keep your stories coming in.

Our baby girl, Ellie, is 30 this month! Can all of you who were at our first conference, when Ellie didn't want to leave her new (now lifelong!) friends, believe it? What an amazing support and friendship group TSSS is, full of wonderful people. Thank you to Arlene and co for making us so welcome all those years ago, we have never looked back.

Ellie will have to wait a little while to celebrate her birthday properly but a small price to pay considering what many are experiencing at the moment. Our thoughts are with all those who are going through difficult times.

Our very best wishes to you all, stay safe and look forward to a brighter Spring and Summer when, hopefully, we can all get out and meet each other again.

Maggie, Phil and Ellie xxx

Chair's Report

Hello everybody,

I hope that you are all keeping safe and keeping well. It has been a very long 12 months and I am just so pleased that we may be coming to an end of this coronavirus pandemic.

Personally, I have struggled a lot. I had to shield from March to mid- June and I was so pleased that I could actually go out with Melissa and meet up with all my friends, even if it was just for a coffee, the simple things in life. So, I had a few months of going out doing whatever, doing all my Xmas shopping etc. only to be told that I had to shield from Xmas Day. I was not a happy bunny at all. So, I was back to walking the dog on my own each day, Steve being home ALL DAY too!!!!! I marked on my calendar that my shielding would stop 20th Feb so was making plans with Melissa and marking dates on my calendar...Then disaster (well it was to me) when it was announced that shielding was going to be EXTENDED to March 31st... what did I do... I locked myself in the bathroom (I really did). So, things have been a bit tough for me but I have been trying to be positive most days. Highlight this week was Steve taking me to a drive-thru COSTA for a hot chocolate to try and cheer me up, he has been very supportive...

I had my first vaccine on 6th Feb and my 2nd vaccine is 2nd May so I'm pleased about that. At least that is something positive. I hope everyone is getting their vaccines soon as we are all now on the vulnerable list.

Steve being the kind husband that he is has booked up several staycation holidays for us. In June we are going to Warner Hotel in Hayling Island for the weekend with his mum and his sister and husband. We are going for a long weekend as Jane McDonald is singing there and Steve's mum likes her. In July we are off to the Scilly Isles for a week. We drive to Penzance, park the car there and get on the ferry (no cars are allowed on the island). I believe that there are bikes that you can use but you will not get me on a bike (unless it is a tricycle)... Anyway, the ferry timings are not good for us coming home so Steve has booked a flight for us. We are flying from the Scilly Isles to Lands' End (a whole 20 mins ha-ha) by the time I get my seat belt on we will be landing. Steve has been telling people I am lucky as I am going on a cruise (ferry) and flying too.

We have booked up a foreign holiday next March. We are going to Iceland (I don't like the cold and the wind)!!!!! We are going for 4 days and it is a jam packed 4 days. We will see the Northern Lights, if we don't see them the first night then we go out the next night. We will also go on a snowmobile, whale watching and lots of other activities. I will be needing a holiday when we come home.

Melissa and Geoff are actually working in the workplace. They were both furloughed for about a month at the start of Covid. I haven't had them in the house since December. Geoff is missing coming over during the week for dinner and misses my roast dinner too. I have been missing them. They actually came over on Sunday but sat in the garden (it was blooming freezing).

I have been busy baking, knitting more as we have welcomed 2 more babies to my family. I have another 2 great-nephews who I haven't met yet. I am hoping to go up to Glasgow as soon as all this nonsense is over so that I can have a cuddle before they become toddlers!!!!!

Well peeps I will finish now.

Please, please all you lovely girls/women STAY SAFE.

Lots of Love

Susie (Mrs TSSS)xxx

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 and have updated it with any vaccine information we have. 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, cancelled all TSSS face to face events. This has been under continuous review, as we are very much aware that everyone is desperate to see each other. As things do not seem to be improving as quickly as we would all like, we will keep this decision under 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 specialists 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/TSSSCOVID**

We are all well, although we must admit how difficult lockdown has been. My gall bladder surgery, like many others, has been cancelled numerous times now. 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. If you are struggling and want a chat do give me a ring on 07947- 554587 I will do my best to help.

Please do take some time to read through the newsletter, even repeated articles have been updated with additional information. Do not 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, depending on lock down restrictions. 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. Do not forget we have a wonderful team of trustees and committee members that are there to help too.

I 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 and the vaccine etc. I always try and give families the time that they need. I support members by phone, email, 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. I 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 me running the office. Carlene remains furloughed to protect her job for the future. As soon as circumstances improve, she will be back.

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.

All Members

Membership is due on the **1st of June** each year. Your support is invaluable to us. Please check your membership is up to date.

If you are paying by standing order (annual £30 or monthly £2.50) please check that your fees are up to date. Thank you for your continued support.

If you usually pay via our online shop, we now have a new way to pay your membership online via our website **https://tss.org.uk**. All you do is click on the JOIN NOW button on the home page and it will take you to our new platform Enthuse. Or you can copy and put this link in your browser **https://tss.enthuse.com/membership**. You can set up a monthly or an annual direct debit you choose what works for you. You will then be directed to our Membership Survey please complete the survey to complete the membership process. The survey helps us ensure we have your consent and ensure the information we have is accurate and up to date. This year we need your membership more than any other.

We appreciate that times are hard for many just now. If you are struggling just at the moment, please let us know. We will do our best to support you, we will not delete your record if you contact us but we can't help if we don't know.

Please ensure you complete the GDPR survey to consent to staying on our database, if you have not already done so. If in doubt please do it again https://www.surveymonkey.co.uk/r/TSSS-Membership. 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.

You can still join via post by cheque or postal order the cost is £35 per year. Payments should be sent by 1st June each year to the TSSS office address (see back page).

GDPR

If you have been a member for many years, please do ensure you have completed the survey by following the link below. 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/TSSS-Membership**

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.

You can set this up by following this link **https://tss.enthuse.com/GiveitupGiveitin**

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/Seminar 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 we are not hosting any Open/Seminar Days due to Covid 19 restrictions. This will be reviewed on a regular basis. Your safety is paramount to us.

Covid 19 and how it affects the TSSS

I thought I would share with you how the TSSS is being affected by Covid 19 restrictions and lock downs. The impact has been considerable, 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. I am so proud to be part of our TSSS family.

With International travel still such a challenge, we think it is unlikely that we would be able to host any International events. We have decided that to do such a large event on-line is not practical and very expensive. 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. The health of the TS community is of vital importance to us.

We continue to review the UK wide situation as our TS community have such a wide range of additional health complications, we must be mindful of everyone's health. Just now it is hard to plan anything in advance and we are now in a position that cancellation would be costly and we just can't take that risk at the moment. We have reluctantly taken the decision not to even attempt our annual conference in October as we know and love. However, if things do improve, we will look at hosting Seminar or Open Days and Friendship Groups. Keep checking of the website for details.

We had to gather up Covid 19 information and support very quickly for our members. We have now added Vaccine information too. Thankfully we work closely with the best specialist 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 was our only option to hopefully protect her job in the future. Carlene understood completely and was supportive of the decision. That means I have had to cover all the work of the TSSS. She will return when possible or at the end of furlough scheme.

I have spent a lot of time looking for grant support. Sadly, we do not 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

TSSS CONFERENCE 2021

We have reluctantly taken the decision not to even attempt our annual conference in October as we know and love. However, if things do improve, we will look at hosting Seminar or Open Days and Friendship Groups. Keep checking of the website for details.

TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

New Factsheets

Available now...

We are delighted to launch our wonderful new Factsheets, printed thanks to a grant from the Society of Endocrinology.

We have two new factsheets available to download free from the website, Factsheet 12 is on Blood Pressure in TS and Factsheet 13 is on the Heart in TS. Our thanks to the team at Oxford University Hospital especially Dr Helen Turner. Dr Elizabeth Orchard, Emma Weingart and Dr Avril Mason in Glasgow's Children's Hospital for their dedication to their patients in preparing the content. We will be circulating them as widely as possible at TSSS and HCP events throughout the country. They are free to download from the website **https://tss.org.uk/information**

Or we can post them on request for a small donation to cover the cost of postage.

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 realise that many of you, understandably, have had a bit of Zoom fatigue and, as many of our wonderful doctors and nurses were helping on Covid wards, we postponed events until the spring. Once dates have been confirmed details will be on our website and social media. We will have a zoom event to launch the new factsheets on Blood Pressure and the Heart. We have held some zoom events on Anxiety, Mindfulness, Cuppa and a chats, Virtual Kids Club, Magic Show and Christmas Party, we have hosted a weekly teens event hosted by the lovely Sam followed by Cartoons with Sam from New York. We are about to host some counselling and mindfulness Zooms and much more.

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.

TS Awareness Day

21st June annually

Turner Syndrome AWARENESS DAY

aims to create greater understanding of Turner syndrome

Turner syndrome is a complex and common genetic disorder that affects 1:2000 live female births. The main characteristic features of TS relate to growth and development but other characteristics may be associated with the condition.

Do **you** have Turner syndrome?
Do you think **you might** have Turner syndrome?
Do you think **your daughter** might have Turner syndrome?
Do you know **someone** who has Turner syndrome?
Do you want to **know more** about Turner syndrome?

Turner Syndrome Support Society

Registered Charity No. 1080507

Girls and women who have Turner Syndrome can benefit greatly from appropriate medical treatment. Sadly however, many are not diagnosed early enough to benefit from treatment or are able to obtain help with other aspects of the syndrome. Those who have been diagnosed often think they are on their own. **They are not**, the TSSS is here for them, their families and friends. The TSSS [UK] aims to deliver the highest standards of accurate, timely and relevant information about Turner syndrome and to offer support to all girls and women with Turner syndrome, their families and friends throughout the UK.

Please contact for more information:-

Arlene Smyth, Turner Syndrome Support Society,
12 Simpson Court, 11 South Ave, Clydebank Business Park, Clydebank G81 2NR
Tel 0141 952 8006 Fax 0141 952 8025
Email Turner.Syndrome@tss.org.uk Website www.tss.org.uk

Wear purple for TS Awareness Day 21st of June! You can wear anything purple and post across social media.

You could draw and decorate a mask, take a photo and post. You can buy lapel pins, wristbands, a mug or a bag, there are plenty to choose from on our online shop.

If you would like to donate to TS Awareness Day please follow the link below...

https://tss.enthuse.com/AwarenessDayAnnually#!/

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
Tracy Glasgow • 07798 914796
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 • 07814 494698
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
richardallajone@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.

Don't forget our on-line shop. We have lots of TSSS goodies available. You can re-new your membership by clicking the ***Join Now*** button on the home page 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 and Twitter

Facebook

Please visit our public page and 'like it', Turner Syndrome Support Society UK www.facebook.com/TSSSUK this is our *official public page*.

There are numerous facebook 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 are given priority, if you have paid your membership and are not yet on the member only groups, 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 users' 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.

We would like to share our concerns and warn you about an American man called Mark Seward, if you are sent a friend request or a message by him, he is in the USA, **it is our advice to block him**. He appears to have developed an unhealthy obsession with the TS Community. This was brought to our attention by the US TS Groups. On investigation here in the UK, his actions appear to have been inappropriate here too. We strongly advise you not to engage in conversation with him.
If you do have any concerns, please contact Arlene.

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 and 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 by sending them a tweet or a direct message about TS or the society. A massive thank you to Ella, Charlotte & Ellie for all their help in raising our profile.

You Tube

TSSS UK You Tube Disclaimer

The information provided by the Turner Syndrome Support Society [UK] and any member of our medical advisory board on our website or You Tube Channel and any other forms of social media is for general information purposes only. All information on the site and our mobile and social application is provided in good faith, however we make no representation of any warranty of any kind, express or implied, regarding accuracy, validity, reliability, availability, or completeness of any information on the site or mobile and social applications. Your use of the site and our mobile and social application and your reliance on any information on the site and our mobile and social applications is solely at your own risk.

TSSS UK You Tube Channel, please visit:

https://www.youtube.com/channel/UCXfR05RKs-RXfRRmMAhM4Mw
Or search YOUTUBE for Turner Syndrome Support Society UK

Please look at 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. and we are very grateful for their support)

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.
https://youtu.be/1VDlRwh-KMU
The TSSS would like to thank Dr G Currie and Dr A Mason from the Royal Children's Hospital in Glasgow for their help with both of these videos.

A guide to cutting patches for Pubertal Induction
https://www.youtube.com/watch?v=9mvOYqYueUc&t=52s

Explain Pubertal Induction in Turner Syndrome
This video was made to explain in detail how puberty is induced.
https://youtu.be/uGYPBtzppFU

Mindfulness Guide to aid sleep with Moya Fletcher
an experienced Mindfulness Facilitator, Person Centred Therapist, Reiki Master & Mindfulness based cognitive Therapist.
https://youtu.be/uGYPBtzppFU

Please share these as widely as you can.

Membership & GDPR Reminder

Membership 2021 is due on the **1st of June 2021** 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.

Get Well Wishes

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

We are thinking of all members who have been ill. We wish you a full and speedy recovery.

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 easyfundraising, on average, we receive £60 plus per month. Don't forget to use it to for all your online shopping, we now have 360 supporters which is a great increase, 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**

TSSS Stands at Conferences 2020/21 all face-to-face events have been cancelled or moved online until 2022

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, just go to: **https://tss.enthuse.com/GiveitupGiveitin**, 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 usual conference date and pay it on the Smarteen Challenge Page below.
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 TSSS (UK) Smarteens Challenge
https://tss.enthuse.com/cf/tsss-uk-smarteens-challenge

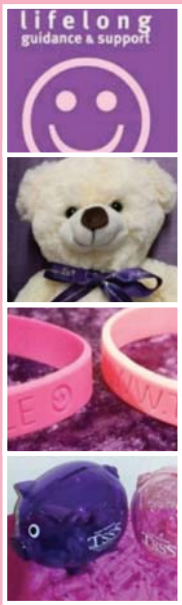
Have fun and thank you for your support.

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 shopping and help us at the same time.

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. **https://tss.enthuse.com/GiveitupGiveitin**

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 – **£277.98** from January and February 2021. Amazon Smile has raised **£223.96** between October 2020 & February 2021, 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.

Hi everyone!!

Just want to say a huge thank you for your support through easyfundraising!

It is wonderful to see new supporters and your help really does mean a lot!

If you are new to easyfundraising, it is a fantastic way to help the society raise funds without any added stress for you.

Simply download the easyfundraising app or head to www.easyfundraising.org.uk and select the TSSS as your cause to support! We all need some retail therapy in lockdown and online shopping has been more popular than ever so by using the easy fundraising app or website and searching your selected retailer, it will automatically take you to the retailer's website or app and generate a donation for the society!

Fun challenge!!

By signing up as a new supporter for the society and using the link below, when you raise £5 for the society, easyfundraising will match another £5!

https://www.easyfundraising.org.uk/causes/tsss/?invite=63K4RE&referral-campaign=c2s

Let's go!!!

Thanks again everyone, *Lots of love Ella x*

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-19 please look at the website to familiarise yourself with the rules we pride ourselves on.

Donations List

October 2020 to February 2021

Our sincere thanks for each and every donation

October 2020

We have received a donation from **Ye Cronies** who support our charity every year. This year they donated **£615,** thank you so much.

We received a kind and thoughtful **£1000** donation in memory of the late **Janis Elizabeth Turner.**

Helen Cleveland kindly sent us a **£100** donation.

Sew So Unique created fundraising t-shirts in memory of **Hope Heavens-Grove.** They raised **£60** for our society.

November 2020

One of our lovely members, **Frances Hunt** kindly donated **£250** to our society.

We received an anonymous donation of **£31.25** including Gift Aid.

We received an anonymous donation of **£125** including Gift Aid towards our 21st Birthday Appeal.

Nicola Lo Celso donated **£62.50** including Gift Aid.

The Keleghan family donated **£15** to our society.

The Oliver family donated **£20** to our society.

Amanda Penfold held a solo event from 5th November to 30th November. She completed a baker's dozen runs throughout the month of November. She is running on behalf of her niece with TS. She has raised **£101** so far.

A donation of **£30** was given via Charities Trust by **David Rothwell**.

December 2020

Caroline Marquis donated **£18.75** including Gift Aid.

Carolyn Brewer donated **£25** in lieu of Christmas cards to our society.

Ruth Tandy donated **£12.50** including Gift Aid in lieu of Christmas cards.

Ella Phillips donated **£62.50** including Gift Aid to our society.

Su Lau donated **£50** to our society.

Mirren McLeod donated **£18.75** including Gift Aid.

The Woodhall family donated **£31.25** including Gift Aid as thank you for the TSSS Christmas party.

Hillary MacDonald donated **£31.25** including Gift Aid.

Sarah McDonald donated **£30** to our society.

The Brown family donated **£30** to our society.

Cathy Tate donated **£25** including Gift Aid to support her granddaughter who has TS.

Hannah Brown donated **£12.50** including Gift Aid.

Carol Wanstall donated **£25** to our society.

This donation of **£62.50** is in memory of my daughter **Penelope** who was born 5 years ago (4 months early and sleeping). Penny was diagnosed with Turner Syndrome and unfortunately her little heart wasn't strong enough, Penelope's story is shared in your booklet. I wanted to make a donation on her birthday to support others.

Jaime Green donated **£25** including Gift Aid to our society.

Jonquil Neal donated **£5** in memory of **Caroline Attenstaedt**.

Annette Pool donated **£37.50** including Gift Aid to our society.

Marte MacBrayne donated **£5** a month to our society.

We received a **£500** donation from **Chemring Energetics UK** from the company's charity fund that all their employees contribute to on a monthly basis.

One of our lovely members, the **Rev'd Mary Railton-Crowder**, sent a donation of **£100**.

We received a kind and generous **£1000** donation in memory of **Sharon** from **the Rainey Family.**

Jessica Otter donated **£10** in lieu of Christmas cards.

January 2021

The Robertson family sent us a **£100** donation in lieu of Christmas cards this year.

The D'Anna family hosted a virtual Strictly Come Dancing competition and the family have donated **£212.50** including Gift Aid to our society.

Hazel Charlesworth donated **£15** to our society.

Lauren Gail donated **£25** including Gift Aid for her lifelong friend.

Catriona Young donated **£10** to our society.

February 2021

Jacqueline Kovalevsky-Rae donated **£25** including Gift Aid.

Mr Vincent Lynch donated **£31.25** including Gift Aid.

Gary Horsburgh donated **£62.50** including Gift Aid.

Rachael Magson donated **£25** including Gift Aid in memory of **Jean Davenport**.

Angela Johnson donated **£56.60** in memory of **Hope Heavens-Grove**.

Melanie Russell donated **£26.25** including Gift Aid to our 21st Anniversary Appeal.

We have received a donation of **£600** from **Tech Data Ltd**. We were nominated by one of their employees, **Kimberley Wells**.

Tracey Aldridge had planned to host a fundraising event on our behalf last April but due to Covid19 it had to be cancelled. She decided to continue with the raffle to raise money and awareness for our society. Tracey successfully raised **£1572** for our society. Thank you to everyone that contributed to this raffle.

Steve & Holly Brayton lost their baby with TS at 22 weeks old in utero. They decide to raise money and awareness in memory of their butterfly. They raised **£1557.50** including Gift Aid for our society.

Tamzyn Barrett donated **£332.50** including Gift Aid in memory of her daughter **Tilly**.

Facebook Donations

We are so pleased 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 set 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 **£1812.88** has been raised between December 2020 and February 2021.

We would like to say thank you to every single person that has contributed to donations through different fundraisers through Facebook. Every penny counts to us.

Thank you all so much for your continued support.

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.

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.

My experience, so far, of living with Turner Syndrome (TS)

This is not a totally happy story but my aim of writing it is to change the rest of the story for the better.

My genetic condition doesn't define me, and I refuse to feel ashamed, or unfortunate, or pity myself because of it. I am 21 and feel I am able to take a perspective on my childhood experiences now and have the resources to articulate what feels like a necessary and long-awaited vocalisation of them.

My earliest memories of understanding I was not quite normal medically was when I was 3. I have an image in my head of me coming out of the operating ward screaming after having had my tonsils and adenoids removed and grommets put into my ears.

This was not something I understood at that age, but I knew my ears and sinuses constantly got infected. I then had hearing tests and, aged 5, got glasses and a patch to correct a lazy eye, put into special classes to improve my hand to eye co-ordination, and got put on growth hormone injections for the next 10 years after being diagnosed.

I remember a nurse coming around to our house one evening with the pen to show my parents how to inject me and then giving me a grey puppy toy and explaining I was "special". This kind of labelling at such a young age got much more internalised and taken to heart than I realised. I then started going to the endocrinologist specialist where I was measured and weighed and sat between my parents and explained every time how I was doing, and it was a very friendly and welcoming atmosphere, and I began to recognise and have a kind of respect for everyone helping me. I also, however, remember comparing myself to other children in the waiting room wondering what was "wrong" with them, and not completely understanding what was being said in the appointments.

I then spent my childhood visiting the hospital fairly regularly, interfering with my school days, for a whole range of things, the most significant being to scan my ovaries to check my fertility aged 10. My sense of self-worth and confidence was impacted by this already, and then I was then told I couldn't have children naturally by my parents, who sat me down and calmly explained it, as gently as they could. It was sadly at the same time my school mates and I were being taught about how babies were made, and I cried and I cried all evening because I did understand it on some level, but I managed to be comforted by the support of my amazingly patient parents and the idea of adoption. I do now feel however as though I experienced much more stress from that experience than I realised, and am disappointed that the doctors didn't have more to say on the possible implications of finding that out at such a young age.

From then on, I have had more serious headaches and migraines, also I assume made worse from the HRT I have been on since 12. I understand on a rational level why I had to have my body investigated during puberty, but the fact that it was done on a ritual basis by one or two male doctors now makes me feel uncomfortable because at that age I had no way to express the shame and anger I felt at having that be part of me, apart from venting frustrations to my empathetic parents. I was also not aware of how that, on top of being much smaller than most of my friends, all of this would negatively affect how I viewed my femininity, sexuality and self-esteem, and lead to self-destructive behaviour.

I've never had a friend with TS despite my parents' trying to help me connect with younger girls with the condition through the support groups of the charity, mostly because it was off-putting bonding over something so painful for me, but also that I am not affected with as many symptoms as other girls are. I've never felt I could articulate the frustrations of all of this to my friends or family without feeling like I am complaining, however I think I have had one too many badly emotionally handled experiences. Some of these experiences include going to A&E twice with panic attacks, to the neurologist and ENT specialist for frequent headaches, and to the gastroenterologist for IBS symptoms, where the doctor picked up a call and talked of a girl my age with a serious condition which I was concerned I had. There was no progress made in any of these interactions, and I feel it has led to me being more guarded and less trusting of the medical world than I would like. I feel I have had to rely on alternative

therapies of all kinds because of this, and this year has been particularly hard on my mental health, as it has been for lots of people. I am in the situation where I feel I need to try EMDR (Eye Movement Desensitisation and Reprocessing) to process the shock of in particular the discovery of my infertility, and it is with pain that I want to improve the situation particularly of the mental health services for children who will be in the situation I was in my childhood.

What I hope for the future is that psychological interventions for women with Turner Syndrome are handled more sensitively, with more time and acknowledgement of the emotions it brings up. It is often not until later, when there is less of a support network around and the brain begins to mature, that people begin to understand the unfortunate implications of their childhood difficulties, and this is no different for children with medical difficulties. It would be beneficial to find some more preventative measures that could be delivered sensitively so as to empower girls as they grow up. I am sure having a specialist that was a woman during my puberty, being given some creative writing tasks to share with other girls and friends, and more information on how to confront social implications in ways that work with my personality would have helped me, I imagine. I'm sure this would be wonderful and more achievable with research into how TS affects women's relationships and friendships, which for me have been damaged by the loneliness of this journey.

I have had some very easy and friendly experiences amongst the ones I describe, heart scans done very professionally, blood tests taken very expertly, and met a lot of emotionally generous doctors and nurses. I have faith that, with the support of women with TS and leading researchers in London, the future will be improved.

Lily

Message from the editor:

Many thanks to the author, it often helps to share experiences and feelings so that others realise that they are not alone in their experiences, or thoughts and emotions.

If any other members (girls, women, partners or parents) would like to share their story please submit your journey to Arlene and we will try and include it in future issues. We will always anonymise the article if required.

My Lockdown Story

Hi everyone

I hope you're all keeping safe and as positive as possible through lockdown.

It's fair to say that the last year has been more challenging than most but luckily, that's where us women with TS thrive!

I think sometimes it can be so easy to forget all of the things we overcome, not just day to day but with our longer-term goals too.

Each victory, no matter how small, should be celebrated so I wanted to share a little of my lockdown story.

For the last 4 years, my partner Dan and I have been saving to buy our first home together. It has been such a journey and there have been so many challenges (as well as positives) for us along the way, particularly this last year!

Just after the first lockdown in March, I was told I needed to shield and this meant house viewings became trickier to navigate. On top of this, about a month after he started his dream job, Dan was furloughed. This definitely gave us a challenge when negotiating our mortgage offers but we were so determined.

For every setback we had, a positive followed.

I had been on a waiting list to have surgery and was so lucky and privileged to be called in last September. (Our NHS are just so amazing!)

After my recovery, Dan was back to work and thankfully, we were still able to set up house viewings and my first trip out of the house was to view the house we now call home!!!

It was such a proud moment when we finally got our keys just before Christmas and to be able to finish 2020 on that note was truly a blessing. Even in the toughest of times, dreams can come true!

So, I guess I just wanted to say that, if things seem tough just now, keep going, you will get there. And it will be worth all the work, patience and perseverance it took to get there.

Remember that women and girls with TS are a force to be reckoned with and there is nothing we can't achieve!!

Just keep your goal in mind each day and remember that every day, you are one day closer to reaching it!

Lots of love, Ella x

Turner Syndrome and me...

Some of you reading this might know me from conferences that I came to a few years back. For those of you who don't, let me introduce myself.

I am 45, and live in Cambridge, and am in the lucky position, in these difficult times, of having a job I love working as a cognitive behavioural therapist with students at King's College Cambridge, and also seeing people privately for therapy sessions. Part of the reason that I got here was the psychological help that I received, relatively late in life, I was pushing 30. I then realised that I wanted to try and do what the therapist I saw had done for me, for other people, which is what set me on the path that I am now on.

He encouraged me to look into the TSSS, which I did and came along to a couple of conferences. I definitely got a lot from attending, so a massive thank you. I thought it would be helpful to share my thoughts about three things that still stand out in my mind from the conferences I went to. The first one is one of the talks from Professor Skuse, which left me with a sense of just how complex the x chromosome is, and how much more there is to learn and understand about it, which opened me up more to the reality of how 'wonderfully and fearfully' we are all made, and how fundamentally mysterious and unique every individual is in terms of their genetic and psychological make up. Having Turner Syndrome and knowing that there is something different about our genetic makeup gives us all the opportunity to know that on a deeper more personal level, and hopefully some wisdom and perspective can come into our lives as a result of that.

Also, a conversation that I had with the partner/husband of one of the women with TS really stays with me. I had the worry at that point in my life, which I suspect a lot of women with TS have, that getting into a long-term relationship with someone and not being able to have a child that is genetically both of yours, would be denying them something. He helped me to see that it would be their choice to make, and if someone chose to be with me, it would be because they wanted to be with me.

Thirdly, and adding to this, it was really helpful to hear people talk about their experience of adopting, surrogacy and also the Mum of a girl with TS talking about her thoughts and response to her daughter's infertility.
I could see the pain that infertility can cause in people's lives, but also the hopeful reality that there are lots of ways to create a family.

I have ultimately spent my adult life, up until now at the age of 45, not in a long-term relationship, and without becoming a Mum. I have seriously considered adopting on my own, and think it is an absolutely amazing thing to do, and admire people who have done it, but things have taken a different path for me. I have ultimately decided that I am fine with not being a Mum, and that my very strong maternal urges are met in other ways. I think my work in some ways satisfies the urge to try and nurture and care for people. Also being involved in my nephew's lives, who sadly lost their Mum to cancer nearly 5 years ago, is also a role I love, with the awareness that I am not and don't try to be their Mum, because I can't be, but I can be a hands on Aunty, 'Aunty Possible' as one of them called me at one point.

I am aware of how incredibly lucky I have been in relation to my health, and reading 'A Cracking of the Heart' by David Horowitz about his daughter who had TS made me very aware of this indeed.

So, thank you for all the hard work that the society does, and wishing all of you very happy futures, wherever life leads you, and whatever part having Turner Syndrome plays in that.

Barbara

Moving house in Lockdown!

Hi everyone!

Hope you are all well and keeping safe through lockdown. Spring is around the corner so hopefully brighter days are ahead!

For all that last year was difficult, I wanted to share something positive that happened to me and my fiancé Jason. When lockdown began last March, I moved from my parent's house into Jason's flat permanently so that I could work from home as my office was closed. I stayed there most of the time anyway so living together wasn't anything new to us, Jason already understood my traits or 'quirks' as I call them!

We have been saving up to buy our first home for a few years, but due to some challenging times over the last couple of years this had been put on hold. Last year, however, the time was finally right. We looked at a couple of houses until we found the house we now call home! We loved it straight away and immediately arranged for a second viewing 2 days later with my mum and dad – it's always good to get that reassurance from your parents! We soon learnt that once you find a house you love you have to act quickly!

We put in a provisional offer and we had a long conversation with a mortgage advisor. This was all new to us, but the mortgage advisor was very helpful and explained every step of the process. Me, being my organised self, decided to use a notebook and I wrote everything down from the beginning, it helped to keep track of fees and progress.

Once our offer was accepted in early October nothing seemed to happen for weeks. We started to pack up the flat in preparation, and once the surveys were completed on the house, everything started to move very quickly! I had spoken to family and friends who had all said once things move it all happens fast but I didn't believe them!

We moved in a week before Christmas, which was a manic time to move but we were really hoping to be in the house for Christmas day! Moving day went well and I was quite proud of myself for arranging for electricians and plumbers to come out at short notice – again this was a learning curve!

We are now settled in to our first home. I am looking forward to when lockdown is over so I can go and buy some pretty things for the house!

I wanted to share my story to show that if you have a goal you can achieve it and it doesn't matter how long it takes or how you get there. I would also say don't be afraid to ask for help or suggestions, my family and friends were a great support to us.

Hope to see you all soon!

Charlotte XXX

TSSS Covid Survey

If you have Turner Syndrome and have had Covid the TSSS would appreciate it if you could please take a few moments to complete our survey **https://www.surveymonkey.co.uk/r/TSSSCOVID**

This will help us support others in the TSSS community in the future.

Thank you so much.

Does Turner Syndrome affect social skills?

In recent years, there has been increasing research into the implications of Turner Syndrome (TS) on social skills.

For example, Suzigan, De Paiva E Silva, Guerra-Junior, Marini, & Maciel-Guerra, (2011) measured the social skills of 52 participants with Turner Syndrome, alongside 33 of their unaffected sisters. They found the mothers of these individuals reported daughters with TS experiencing social difficulties compared to their healthy sisters. This was both within the family, and outside the family at school/work. Interestingly the girls with TS themselves did not identify social difficulties to the same extent as their families, when interviewed separately. It was argued by the authors that this may be due to a possible lack of awareness on the girl's part of their own difficulties. Wolstencroft, Mandy, & Skuse, (2019) also investigated this area. However, unlike the previous study, they also looked for symptoms of other neurodevelopmental disorders (conditions affecting the brains ability for learning, focusing, social skills etc) and mental health issues that the participants had. These included Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and conduct disorders. The results of this study showed that along with higher rates of mental health issues, those with TS had higher rates of peer interaction problems than individuals not diagnosed with TS. Despite the findings by these and other researchers, the underlying causes of the specific problems faced by those with TS in relation to social skills are still being debated. Therefore, when required to complete a piece of my own research as part of my studies at university, this was the topic I chose to focus on.

As I have TS myself, I understand first-hand how difficult everyday social interactions can be when you have TS. There was also a significant difference in my own project. The group of TS participants were shown to have a lower mean score on the Social Skills Inventory (SSI) than the non-TS group. This is a psychometric test which measures 6 basic skills underpinning social interaction (e.g., emotional sensitivity, social expressivity). An overall level of social competence is gathered by adding the scores in each of these areas.

Some other research has suggested that deficits in facial emotion recognition (identification of emotions from facial expressions), particularly in the recognition of fear, and other social cognition abilities, such as eye gaze processing could be a factor in explaining social difficulties in TS (Hong, Bray, Haas, Hoeft, & Reiss, 2013), (Mazzola et al., 2006). In contrast it has been suggested that social difficulties in TS may be in part the result of visuo-spatial processing deficits (Anaki, Zadikov-Mor, Gepstein, & Hochberg, 2018). Overall, these findings provide more evidence to support a specific difficulty in terms of social interactions in TS. This is important, as it could lead to the development of interventions to help improve the social skills of those with TS. Although such interventions would not completely get rid of any issues, they may mean that difficulties are reduced to a less significant level, thereby increasing the quality of life of individuals with TS. It will be necessary to conduct more in - depth research to further establish knowledge of the complex nature of the wide range of difficulties experienced in TS.

Lauren Judd

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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

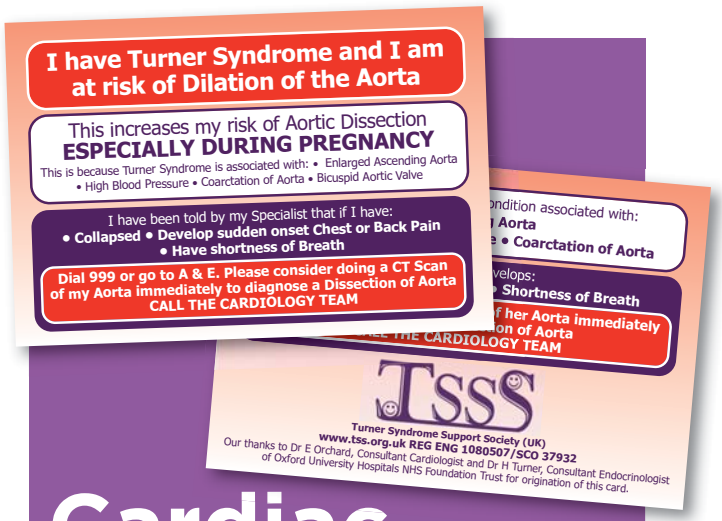
Smiling is infectious, you catch it like the flu

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.



Cardiac Alert Cards

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

We can 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 healthcare 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 stamped addressed envelope (S.A.E.) 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.

The Scottish Government recently held a virtual session called **Reducing Health Inequalities.** This concerned women and the British Heart Foundation were involved in the afternoon sessions. The talks will be available online and are mainly about how women are affected by coronary heart disease. This is obviously an important issue for all women, not just women who have Turner Syndrome. There is also lots of advice available from them online, as well as related subjects like valve disease and pregnancy in women with heart issues. Well worth looking at.

https://www.bhf.org.uk/informationsupport

TS International News

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.

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.

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 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. 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. They also have some interesting webinars available, do have a look at their website **https://endo-ern.eu/.**

I continue to be a European Patient Advisory Group (EPAG) even post Brexit.

EuRReCa

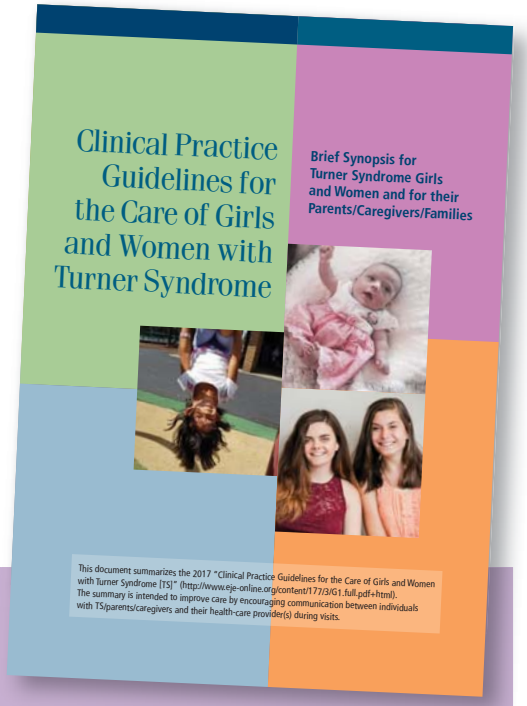
I am a proud member of the **EuRReCa** project. This is very exciting, working to create registries on Rare Conditions across Europe. I do enjoy taking part and learning from the others involved in the project. Do have a look at their website **https://eurreca.net/**

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 available and free to download from our website **www.tss.org.uk.** They have also been printed and are available in printed copy for a small donation to cover postage via the donate button or send a large A4 SAE to the TSSS office (see back page) Please 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 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, Shannon McMullen and Jillian Bryce.

Office for Rare Conditions Glasgow

We have had a super week raising awareness of Rare Conditions and attended numerous virtual Rare Conditions Events.

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

www.facebook.com/ORCGlasgow

https://twitter.com/ORCGlasgow

Awareness of Rare Conditions 2021

We were very proud and grateful to Hayley Cleaver and Emma Fitzpatrick who proudly shared their story and flew the flag for us at the recent Rare Disease Day Four Nation Event. You can watch the recording at **https://vimeo.com/517125822?mc_cid=7f94fd042a&mc_eid=UNIQID**

Thank you so much ladies for your continued support. I am so proud of you both.

You can watch the Rare Disease Awareness Video on You Tube **https://youtu.be/TkZVZgSZ6-8**

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

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

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Thank you to all contributors to the Spring 2021 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 15th May 2021.

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Disclaimer

Not all the views and opinions expressed in the newsletter are necessarily those of the Turner Syndrome Support Society (TSSS). If you would like clarification on any issue please contact Arlene Smyth at the TSSS office.

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