VOLUME 6: ISSUE 24: SPRING/SUMMER 2022

AspecTS

Charity Reg No. 1080507 Scottish Charity No. SC037932

Health tips for the over 40s and beyond!

Our lovely women at our Annual Conference 2019

Check out our great new guide!

See page 7

TS Awareness Day

21st June - see pages 8 & 9

TURNER SYNDROME SUPPORT SOCIETY NEWSLETTER

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Please remember to renew your membership – see page 6

Editor's Message

Hi everyone and welcome to the latest edition of AspecTS.

It has been a really difficult period (again!) for a lot of people and Arlene, Carlene (and others) have been working so hard to keep the society running as smoothly as possible and to provide as much support as they can to members and others affected by TS.

There have been, sadly, illnesses and bereavements over the past few months and our thoughts are with all those affected and their families'. Arlene and Susie have both had a difficult time with illness and we wish them well.

But there have also been some wonderful acts of kindness and support for friends (and strangers) and the TSSS which you can read about elsewhere in this edition. We are never surprised at the acts of kindness and generosity of the TSSS members and their families as we know, and constantly get reminded of, the wonderful nature of our members.

Many thanks to all our contributors and please keep the articles coming in, your personal stories and experiences are so valuable to share with our members and really do help.

We recently welcomed a new member to our family when Laura and Jamie (our son and brother) became the proud parents of baby Oscar. Ellie has not yet seen him as she is in Florida, belatedly celebrating her 30th birthday, the trip had been delayed due to Covid, and Ellie is desperate to get back to give Oscar a cuddle. Ellie has been kept going with many pictures.

Our very best wishes to all and looking forward to face-to-face meetings and holidays!

Hope to see you all soon.

Maggie, Ellie and Phil

(the editors)

P.S. Please don't forget to renew your membership and confirm your details

Chair's Report

Hello everyone,

Stephen and I are hoping that everyone within the Society is doing well. At last, we are gradually getting back into a "normal life" or as "normal" as things can be. Stephen is now going into his office about twice a week and working from home the rest of the week. I am hoping that he will soon be in the office 5 days a week, I am keeping my fingers crossed!!

I am sure that you all know that this years' conference will not be happening. Park Hall Hotel cannot host our conferences any longer as they have gone into liquidation.

Arlene, Carlene and the Committee have all been working hard over the past few months trying their best to find a new venue but it has been so difficult to find somewhere suitable with only months to go this year. As soon as we find a venue for next year, we will let you all know where, when, and also costs etc.

We decided to have a Social Weekend in Blackpool 13/15 May. At the same time we can look at the Village Hotel where we are staying and it could be an option for future conferences. I am looking forward to catching up with members and their families and it will just be lovely to see everyone for the first time in over 2 years. It just isn't the same having ZOOM or telephone meetings, is it?

I have been very lucky in that even though I was classed as "vulnerable" when it comes to COVID19 I was very careful, and didn't catch it. Steve, Melissa and Geoffrey, all caught it at different times all this year. Steve was very strict with me especially when I had to shield and he allowed me to ***"walk the dog on my own once a day"***, he was very kind, wasn't he?

We had some very bad news in March, one of our founding trustees, Sandy Holmes passed away. Arlene, Carlene, Steve and myself all went to the funeral in London to pay our respects. It was a lovely service and she will be sadly missed by everyone within the "Turner" family.

Steve and myself along with 3 other members of Steve's family all went to Iceland (not the shop !!!) in March for 4 days. Guess what... it was freezing cold!!!! We had a lovely time and we were all exhausted when we got home. All excursions were organised for us so it was a jampacked few days. I didn't buy much as everything was so expensive (even buying wool was too expensive). The only thing I bought was a fridge magnet and that cost £8.00!

The Swindon Friendship Group are having a social meet up on 28th May. We are meeting up in Robins Farm for lunch. If anyone would like to join us on the day, please get in contact with Arlene for more information. My dad will be visiting us during this time so this will be his first introduction to the Turner family. He hasn't met anyone else apart from Kylie so it should be good for him to meet other girls or women with TS.

We have not booked a holiday abroad this year. We are waiting to maybe next year. My health over the past 6 months has not been good. I am now oxygen reliant when I am outside the house. Holiday Insurance is now sky high for me now because of my COPD. So, this July we have decided to go back to the Scilly Isles where we went last year. We stay in a beautiful B&B right next to a lovely beach. Definitely a place where you can relax, which is just perfect for Steve.

Melissa and Geoffrey are doing well. Melissa is still working at the nursery. I think that she has been working there for 11 years now. Geoffrey started a new job last summer and now works at JCB as a Trainer. He is really enjoying himself there and just loves teaching.

Well, I will end now. I hope that everyone stays safe.

Lots of Love

Susie (Mrs TSSS)xxx

Arlene's Report

I hope this newsletter finds you all safe and well, as things start to open up and we start to meet again. Please forgive the delay in sending this newsletter.
After such a difficult few years it is good to have things to look forward to. I appreciate for some of you it is also a very anxious time. We are here for you should you need support. Having escaped Covid for two years I finally got it. It is certainly more than a cold for many, and I have been left feeling breathless and very tired.

We received the sad news that one of our founding trustees Sandy Holmes sadly passed away. Sandy was a kind, caring, inspirational woman and will be greatly missed. We want to pay tribute to Sandy and celebrate all she did for the society over many years. If you have a story or a message, you would like to share with us please e-mail me at turner.syndrome@tss.org.uk and we will print them in the next newsletter. We have also received many donations in memory of Sandy which will be acknowledged fully in our tribute to her.

Having cancelled all TSSS face to face events for so long. I was looking forward to things improving and was enjoying preparing for our conference in September. To then get the shock news that Park Hall was going into liquidation was very upsetting for us all. I then spent weeks seeking alternative venues across the country, there is just no suitable availability, it is like everyone is fitting the last two years into this year. We have very large and complex needs, so it is a challenge to find a venue. The trustees, committee members along with Carlene and myself have worked so hard to find somewhere. Thank you to the members who very kindly shard some possible venues. So, it was with the heaviest of hearts that we took the very difficult decision to postpone until next year.

The good news is that we have three potential venues for next year. Both Carlene and I have visited them, and the committee will visit them shortly, and we will make a final decision soon. So, start saving for next year's conference. I will share the exact date as soon as we have confirmed a venue. It will be September or October 2023.

We know how disappointing this is for you and that is why we have added more Open Days and the friendship groups are now starting to meet in person which is great. Please look at the 'important dates' section and the Open Day notice for more details.

I appreciate that many of you are, yourselves, shielding. This is a really difficult time for all of us. 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.

We continue to do the normal day to day duties that are required, such as speaking to those who have had a new diagnosis, I always try and give families the time that they need. We support members by phone, e-mail, Facebook, messenger, twitter etc. We 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 me and Carlene running the office.

We now have a new database to work from which will hopefully help us work more efficiently. Carlene has worked so hard learning the new system and it is very different. In our next newsletter we will be able to share with you how you can check your details and update your address etc via the portal. So, watch this space.

The committee have continued to work hard and had many meetings over zoom in the last two years. We did not manage to meet in person in January or April so hopefully, third time lucky, we will in September. Hopefully, planning conference and some great events. We can't wait to see each other.

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 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.

You will see inside your newsletter we have enclosed a copy of Lifelong Guidance & Support. In November it will be twenty years since we launched the book. It is still as valuable today as it was then, and we now have a second edition. This book is special for many reasons. For me it for filled a dream I had had since Kylie was born. I wanted to provide accurate information for families and doctors alike. I was told that it would never work, and we would not be able to produce a book that was as useful to the doctor as it was to the patients. Eventually Ruth from Ferring believed in me and provided us with funding through an educational grant to produce it.

An amazing team of members, trustees, committee members, doctors, nurses, myself, Lynne, John & Christine from Harlow printing, Helen Lawn, Ruth and many more worked hard to produce the book. Not only did I achieve my dream, it was on my 40th birthday we launched the book at the BSPED conference and as I approach my 60th birthday I can't help but feel so proud to be part of this amazing TSSS family.

This book has been given out to many families, doctors, nurses, GP's and other professionals working with TS families. It has been sent to many other countries in the world. Please enjoy the book if you don't already have it. If you do have it already, please take the enclosed book to your local GP, Practice Nurse, Dentist, hospital specialist or library and ask them to use it to learn more about Turner Syndrome. Ask them to share it with students and colleagues to raise awareness and understanding about TS. Thank you in advance for your support. Should you want more copies please e-mail the office and we will get them sent out to you.

Take care and stay safe
Best wishes

Lady Arlene x

Aortic Dissection Trust

We have been contacted by Keith at the Aortic Dissection Trust as we have a lot in common with both of us raising awareness about Aortic Dissection and hope to work together in future, helping to raise awareness. We hope to do a webinar in the very near future. Have a look at their website.
https://aorticdissection charitabletrust.org/

Important Dates

TS Awareness Day
21st June 2022

Leeds Awareness Open Day
25th June 2022

International Growth Awareness Day
20th September 2022

Belfast Open Day 5th November 2022

Glasgow Open Day date & venue TBC

Welsh Open Day date & venue TBC

Arlene's Diary Dates

European Society Endocrinology (ESE) Conference in Milan
21-24th May 2022

European Paediatric Society Endocrinology (ESPE) Conference in Rome
15-17th September 2022

British Society Paediatric Endocrinology Diabetes (BSPED) Conference in Belfast
2-4th November 2022

British Society Endocrinology (BES) Conference in Harrogate
14-16th November 2022

All Members

Membership fees are 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 activate your membership. The survey helps us ensure we have your consent and ensure the information we have is accurate and up to date.

We appreciate that times are hard for many just now. If you are struggling just now, 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.

If you are a long-standing member, please ensure you have completed the GDPR survey to consent to staying on our database. If you are not sure if you have done it already, 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).

40 plus booklet

We are delighted to say that we have a new updated version of ***"Health tips for the over 40's and beyond!"*** printed. This booklet is written by ladies with TS for other ladies with TS. It is not meant to be medical advice, more things to discuss with your consultant. Our thanks to Hayley Cleaver and the many ladies who contributed to the booklet.

If you have not already received a copy, please email **turner.syndrome@tss.org.uk** to request one. A donation towards the printing and postage is always welcome via the website **www.tss.org.uk** donate button.

Covid-19 Survey

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**

TSSS Conference Postponed 😢

TSSS CONFERENCE 2022 is regrettably postponed until 2023, date and venue to be confirmed. Keep checking the website for more details.

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?

TSSS

Turner Syndrome Support Society

Registered Charity No. 1080507

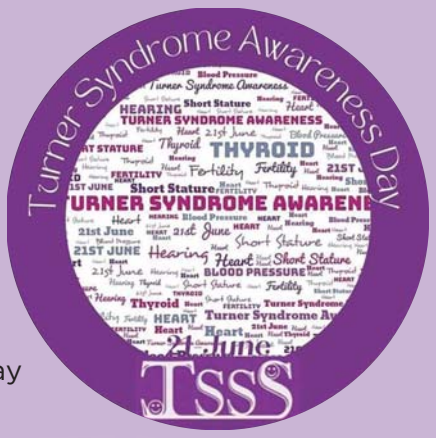
Girls and women who have Turner Syndrome can benefit greatly from appropriate medical treatment. Sadly however, many are not diagnosed early enough to benefit from treatment or are able to obtain help with other aspects of the syndrome. Those who have been diagnosed often think they are on their own. **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

Thank you to everyone who helped and supported last year's TS Awareness Day on the 21st of June. We saw lots of purple worn in photos in aid of our Turner Syndrome Sensational Salute, raising awareness and vital funds, we loved them all. Across social media we had #Shout out for Turners, such a great selection of the amazing posts. Thank you to our fundraising and social media committee chaired by Jane and Ella for their ideas and all the hard work promoting it.

TS Awareness Day 21st June 2022



This year 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

This year we are continuing our **#ShoutOutForTurners** after it got such a good response. Please help us turn Facebook, Instagram and Twitter **purple** and raise some awareness on the 21st of June or any day that week. Tag your favourite celeb, ask family and friends to share, re-tweet. Don't forget to tag us in it.

www.facebook.com/TSSSUK

https://twitter.com/TurnerSyndSoc and my own is https://twitter.com/TSSSARLENE

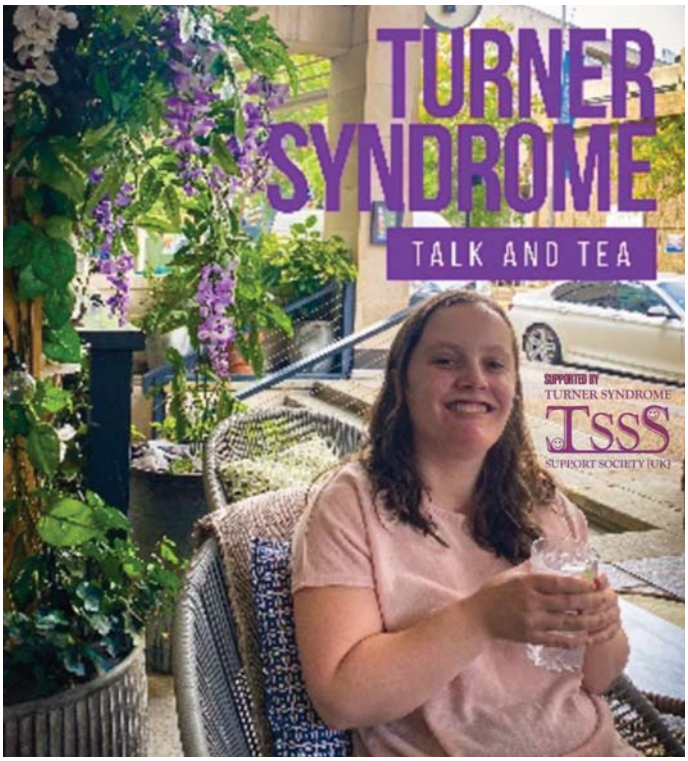
TSSS Instagram @tsssukofficial and my own is @astsssuk12

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

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

Emily's Podcast

We are getting close to a year since I launched my podcast, it is crazy to think it will be a year on the 15th of June. I am getting such nice feedback from all my episodes, the one thing I love is that people from different parts of the World are messaging me to say thank you for talking about Turner Syndrome because it is not talked about a lot where I live.



It's amazing what can be achieved if you work together. This podcast is nothing, and would not be the same, without its guests, so thank you.

Turner Syndrome Talk and Tea now has 4.7 thousand plays overall, and 54 episodes so far. I try not to dwell on the numbers but when you think of that many people in a room it's quite staggering. A very popular episode has been Arlene's which has 200 plays now and I have had lots of great feedback from Prof. Gerry Conway's episode. It was very interesting to interview a doctor about Turner Syndrome as he has a wealth of knowledge.

If you or someone you know would like to be on my podcast, then just message me and I will be so happy to hear from you. I am always looking for guests to interview whether that be women with Turner Syndrome, their parents, siblings or doctors.

Emily x

My social medias where you can message me are:

Instagram https://instagram.com/turnersyndrometalkandtea?utm_medium=copy_linkn

Facebook https://www.facebook.com/EmilySeymour24

Twitter https://twitter.com/es_eymour?fbclid=IwAR2_PIoSVi47yeab3xnQFdPv0ae3NSEWwQahTHMIvloXbf_qetPOQPumQ1w

Emily, I just can't thank you enough for continuing your excellent Podcasts. I tell everyone I meet about them, and we are so proud of you for taking the initiative.

If you have not already listened, please do so. It is just so wonderful listening to such inspirational stories. Well done and thank you so much.

Arlene

International Conference

As much as it breaks my heart, I cannot see how we can go ahead and host an International Conference. International travel is still not back to pre-pandemic levels.

With the degree of uncertainty, and a worldwide economic crisis, it makes it hard to plan. Committing to an event is much more difficult and holds much more risk now than there used to be. Thankfully, we suffered no financial loss because of the Covid cancellation. It important to protect the society from any financial risk and therefore cannot take any risks. We worked on the international conference for 4 years planning and organising. Then Covid hit and spoiled it all.

I do however hope to host a ***'Meet the Expert'*** event where we ask expert speakers to come and share their expertise on TS with other health care professionals. To which we could add on a day for the TS families. I am not sure when that will be, but I do hope it happens.

Counselling Sessions

for members of the Turner Syndrome Support Society UK

The Turner Syndrome Support Society UK (TSSS) is delighted to offer members of the society the opportunity to benefit from counselling with Moya Fletcher. These sessions will be one-to-one with Moya via zoom and in confidence. We have received a charitable donation from Pfizer which has been matched by the TSSS. We can fund 8 sessions per member for a total of 40 members. We are very pleased to be able to offer a service that will directly benefit many members of the TSSS.

Moya Fletcher is a Person-Centred Therapist, Facilitator, Teacher, and Life coach with a Diploma in Counselling. Moya has a person-centred approach and works in a holistic way to offer a warm and secure relationship and environment where you feel safe to explore and express your emotions, feelings, and concerns. Moya will endeavour to help support you on your journey of finding the right answers for you, building on your own resilience. Using mindfulness and a cognitive behavioural framework, together you will explore issues and your thoughts, to discover alternatives, developing a new perspective.

Many of you will know Moya from the mindfulness sessions at conference and online. We also ran some pilot counselling sessions to see if it is something that would be beneficial to the members. As you will see below, feedback was excellent.

Here are a few quotes from our evaluation forms:

"I just wanted to say how positive L has become since having her session with Moya. She has started to make more positive statements."

"Mum and I both agreed how nice it was speaking to Moya during our sessions. We both learnt meditation exercises that we will be able to use both now and in the future."

"I felt Moya had a better understanding of me and how my mind is due to her knowledge of TS which is unique to any other counsellor."

We will offer an 8-session experiential course, where members are encouraged to consider their own life situation in a non-judgemental environment, through discussion and learning, which provides the scaffolding for change.

You will have the opportunity to experience mindfulness, to develop personal awareness and confidence. To consider how our thinking impacts behaviour and understand and manage our own stress/anxiety. To understand the importance of setting goals and celebrating achievements.

To help support members who have struggled with anxiety especially post-pandemic, these sessions will help you find coping strategies and learn skills that can be used for years to come.

The therapeutic hour offers a safe-space in which you can explore options, share feelings, and find your way forward, with understanding, confidence and an enhanced sense of wellbeing and positive mental health. The sessions are completely confidential. The only information shared, in the strictest confidence, with the TSSS are the pre and post course questionnaires, attendance, and evaluations.

As we have limited places available, and we expect to be oversubscribed, we do have to have criteria to ensure we support as many girls, women with TS, their parents and partners across the membership, that we can. All we ask is that you are an up-to-date existing member of the TSSS (before 1st June 2022). We do expect you to commit and attend the agreed sessions, which will be at a mutually convenient agreed time with Moya and yourself, to complete the pre and post questionnaires and complete the feedback evaluations. If you miss or end your sessions early without informing us, you will be expected to reimburse any costs involved, as you will have prevented another member benefiting from the service.

To benefit from the service and apply for a place please complete the consent form, using this link: **https://www.surveymonkey.co.uk/r/TSSSCounselling**

TSSS Website

Please check out 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. We are a small team please allow 2 weeks for your order to be processed, packed, and dispatched. We use 2nd class post for smaller items and Parcelforce for heavy items. 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

Please visit our public page and 'like' it, Turner Syndrome Support Society UK, Face Book page & like us 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).

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.

Twitter

We are on Twitter the TSSS official address is **https://twitter.com/TurnerSyndSoc** and 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 and 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 and Emily for all their help in raising our profile.

Instagram

@tsssukofficial
@astsssuk12

TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

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 applications 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.

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 ones. 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.

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 £80 plus per month. Don't forget to use it to for all your online shopping, we now have 364 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, thank you so much to those of you who have signed up we now have 305 supporters and collectively raise on average £60 per month. So, please choose us when shopping via amazon Smile and we get donations without any cost to you. **https://smile.amazon.co.uk/ch/1080507-0**

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**.

TSSS Goodies

Please do take a look at the online Shop on the website
www.tss.org.uk

We have recently updated the merchandise; 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
- ***"So, you are considering a partnership – what does Turner Syndrome mean for us?"*** Partners booklet.
- ***"Who is the Woman I am Less than Anyway"*** Self Esteem booklet.

Fact Sheets Series on numerous subjects can be found on our website, do take a look they all contain great information and tips: **tss.org.uk/information/fact-sheets**

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** or **https://tss.org.uk/news/283-give-it-up-and-give-it-in-appeal**

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 a penny yourself is to join Easy Fundraising. **https://www.easyfundraising.org.uk/causes/tsss/**

Thank you to all our Easy Fundraising supporters – we raised **£744.44** from June 2021 to February 2022. Every penny helps thank you all so much. Keep up the good work!

Please support us when you shop on Amazon Smile, and Amazon will donate to Turner Syndrome Support Society, at no cost to you. Between July 2021 and April 2022, Amazon Smile has raised **£601.97**, thank you all so much. Please support us when you shop on Amazon Smile at **https://smile.amazon.co.uk /ch/1080507-0**

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

We are registered with the Fundraising Regulator, and we can assure you that your data has and always will be 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. https://www.fundraisingregulator.org.uk/

Donations List

December 2021 to April 2022

Our sincere thanks for each and every donation

December 2021

A big thank you to **Charles George Brookes** for the generous legacy left in his will.

We have received a kind and generous donation of **£1000** in memory of the late **Mr Stephen Southall**. This donation was left to us in his will, as a thank you for all the support we gave his daughter with TS.

Cheryl Jennings donated **£37.50** including Gift Aid to our society.

Alex McCulloch donated **£125** including Gift Aid to our society.

Annabelle Lane donated **£204.96**, as part of NCS.
We decided to raise money for TSSS as one of our members has been diagnosed with Turner Syndrome. We did this through various activities in our community whilst handing out leaflets to raise awareness and encouraging people to donate to our GoFundMe online. Our activities consisted of a sponsored walk around our area in fancy dress, a sports day for children in Hinksey Park with events for them to take part in and a refreshment stand to raise money.

We have received an anonymous donation of **£250** including Gift Aid.

We have received an anonymous donation of **£100**.

One of lovely members, **Seonagh Davidson,** nominated us to receive a donation of **£325** from a local event in her area that she helped with.

A local estate agents created a Monopoly board themed around our town to raise money for charity. We got involved by producing cards to go with the boards and wish for the money we've raised doing this to go to the TSSS.

One of lovely young members **Ruby Taylor** raised **£162.50** including Gift Aid for our society. She made sandwiches at her daddy's work and then sold them to all the other offices to raise awareness and money for us. Well done, Ruby!

January 2022

We have received a kind donation from **Chloe Weatherhead** in memory of her daughter **Gracie**. Chloe donates all her profit from Gracie Glass to our society every year. This year she has donated **£1,397.50** including Gift Aid.

One of our lovely members **Claire Alexander** donated **£200** in lieu of Christmas cards from Norfolk Recovery Services.

A lovely member **Michelle Drake** donated **£12.50** including gift aid in lieu of sending Christmas cards this year.

Susan Porter donated **£25** to our society in lieu of sending Christmas cards, to help us continue to support her granddaughter, **Emma Darnell**.

We have received a donation in memory of baby **Willow** from family and friends of **Miss Paris Read**. **£100** was donated in lieu of flowers.

February 2022

We received a lovely donation from **Lisa Berlin MacQuarrie** and customer at Holy Loch Coffee Shop. They donated **£210** that was raised from selling raffle tickets on behalf of the TSSS.

Jo Brew donated **£100** to our society.

June Tallent donated in Loving Memory of **Sandra Murray**, *Our Beautiful, Precious & Much-Loved Sister, Auntie & Great Auntie. We All Love & Miss You So Much. God Bless.*

March 2022

One of our lovely members **Kiara Thompson** wanted to raise awareness and money for our society. So, her dad decided to donate some money from the profits of their business Nickel & Ross to our society from February 22. Kiara worked hard and supported this by selling products to her teachers and friends. They donated **£113.50** to us. So, thank you to all who donated to Artisan Intelligent Hygiene & Nickel Ross. Well done, Kiara!

We have received a donation of **£917.05** in memory of the late **Mr Steven Udell** from his family and friends.

One of our members **Jess Haslam** has donated **£26** from a collection tin that she has.

We have received an amazing and generous anonymous donation of **£5000**. This person has been a great supporter of our society for many, many years. We greatly appreciate their continued support.

One of members **Ann Harvie** donated **£150** to our society.

We have very kindly received a donation of some laptops from one of our members **Eva Krogh's** company **Veritas Technologies**. This will help us greatly with the day to day running of the society.

April 2022

Paul Bond donated **£187.50** including Gift Aid to our society.

One of our members **Anthony Smith** decided to donate his pub quiz winnings of **£92** to our society. Thank you to him and the team at the Three Pigeons Inn.

A friend of our member **Ellie Hatcher** kindly donated **£25** to our society. A friend of **Pat Griffiths** made her a vase and wouldn't accept payment, so she made a donation to us instead.

Facebook - Meta Donations

We are so pleased with the response we have received with your donations through our Facebook- Meta 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 **£4,400.39** has been raised between November 2021 and April 2022.

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

If you would like to know how to set up your own birthday fundraiser for our society, please follow the link below:

https://www.facebook.com/help/1910205189301966

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.
https://www.justgiving.com/turnersyndrome

OUR CONDOLENCES

Our sincere condolences to all friends and family of our dear friend Sandy Holmes, a full tribute will be available in the next newsletter.

Very sadly, several families have lost babies with TS. Our sincere condolences to all the families that have been affected.

You are all very much in our thoughts.

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 click on 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.

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?viewMod\e=presentation

Healthy sleep tips for children – NHS

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

https://www.thechildrenssleep charity.org.uk/ professional.php

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

Dealing with hair loss

Hi everyone

For those of you who don't know me, my name is Joan, I'm 58 years old and live in South Wales with my husband Steve.

I was diagnosed at 16 with Mosaic TS which came as something of a shock to myself and my family but, we coped, and I did reasonably well in school. especially in English and History.

I sailed through my twenties, thirties and 40's but in 2017 I had to have a total hysterectomy which, over time left me with increasingly thinning hair as the menopause hit. It happened gradually. I always had fine hair, but I started to notice it receding badly at my forehead and at the sides. I hid it well with the help of my very talented stylist, but it was causing me distress, not least seeing the vacuum cleaner brushes clogged up with hair every week.

My best friend knew how upsetting it was for me, so she did some research on my behalf and discovered a system called The Integrated Mesh Enhancer System. I found a company called Hair Solved who offer this system and had a video consultation with them. The lady recommended I visit my GP but, she was almost certain I had frontal Fibrosing Alopecia and she thought this system would be suited to me. My doctor confirmed this diagnosis but said there was very little she could offer by way of medical intervention or treatment.

I made an appointment to visit Hair Solved in Bristol, with Steve along for moral support, and I decided to go ahead and have the system fitted. I have never looked back. It was expensive, things like this never come cheap, but as I had the diagnosis there was no VAT to pay.

The system involves a piece of very fine mesh being placed on your head and your own hair is pulled through the very fine holes, the panels of real hair attached one by one and cut and styled to whatever length you want. You go back every 6 weeks or so to have it adjusted as your own hair continues to grow. Every 6 months you have a realignment where they remove the system entirely and reinstall it again. After 24 months the process starts again with a completely new system, so it essentially lasts for 2 years.

I hope that any of you ladies who are in the position I was in will drop me an email. Hair Solved have salons in Glasgow, Manchester, Bristol and London if anyone would like to check them out. They are also on the usual social networks Facebook and Instagram.

Joan

Joan, thank you for sharing your very personal story. I know it will help other ladies. There are also several shampoos available such as Nioxin and many others. If you have any tips that have helped you please share them with us. If this is something that is affecting you, we could do some research.
Kind regards Arlene

Volunteering in Romania Update

For those who don't know, a quick recap. Since July 2019 I have been volunteering in Romania with a charity that works alongside the Roma Gypsies. Mainly working with the children and families but lending my hand to anything that needs doing.

The last six months in Romania have been difficult but very rewarding. Covid restrictions have limited the work we want to do with the Roma people and in True Turner's fashion I have also had some health problems meaning I have needed to spend periods of time in the UK.

Despite the challenges, Jessica, who runs the charity and I have managed to set up a mother and toddler group in the Roma village. The parents can bring their pre-school children to the centre where they have a safe space to play and the parents can have a coffee and relax. We all have a great time getting covered in glue and paint, parents included!

When the weather and Covid restrictions have allowed, we also had some sessions for the older children with games outside. A donation from Belgium meant we were able to give out clothing, and beds and bedding. I could have done with a few extra inches when lifting boxes and mattresses but gave everyone a laugh as I disappeared behind them!

At Christmas, a team came over from the UK to help give out family shoeboxes with toiletries and toys in them through the Amen Trust which collects boxes in the UK and sends them over to Romania.

During April, a mission team came over from Belgium. Happily, restrictions had been lifted. We had a great week together with the days starting at eight in the morning and finishing at eight or nine o'clock at night.

We were able to run a holiday club for the children with three sessions over the week, and also give out food parcels to the villagers

The week ended with a worship service for the village. Seventy people attended and we finished with hot dogs and doughnuts. It was an amazing time.

I am writing this while having three weeks in the UK to catch up with hospital appointments and friends. Also, to get some rest and relaxation.

Dinah

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

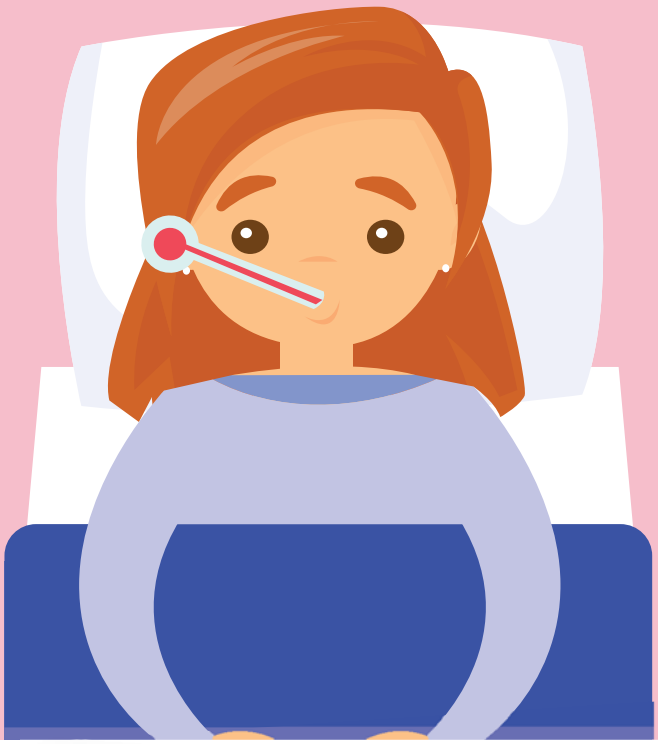
Scottish Friendship Group
Arlene Smyth • 07947 554587
turner.syndrome@tss.org.uk

Get Well Wishes

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

A few members have recently had surgery, we wish you all a speedy recovery.

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



Smiling is infections

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.

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.

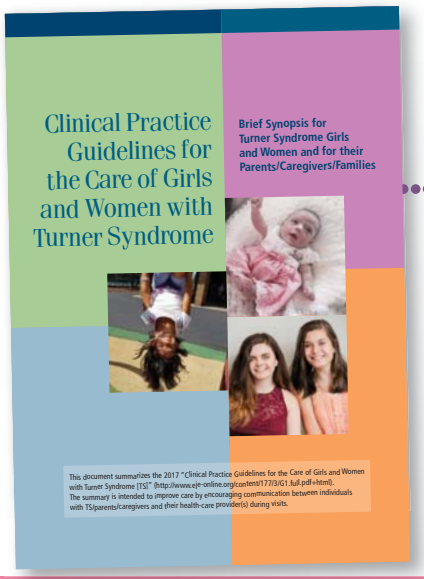
I was unable to meet up with the other members as the date clashed with another event. It is lovely that they are having a face-to-face meeting again.

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 situation and communicate with the other TS groups about future conferences. We are thinking about circulating a survey to everyone over the summer to see what everyone thinks about travel and large events taking place. Do take a look at **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.



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

Endo-ERN

I am a proud member of **Endocrine European Reference Network** and I am looking forward to seeing some of them in Milan at the ECE conference. 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 EuRReCa project through a virtual meeting now. They are working hard gathering data on Covid 19 and how it is affecting those who have rare endocrine conditions.

I-TS

I am pleased to share with you the latest news about I-TS.

Over the last few years, the registry platform that is used for I-DSD and I CAH registries was also beginning to be used to enter cases of Turner Syndrome. To facilitate this further, a new module for TS is being developed over the next year.

The I-TS website **http://i-turnersyndrome.org** has recently been launched and patient information sheets and consent forms for TS are now available and can be used to enrol patients in the current registry. So, if your doctor asks you to enroll, you will know what it is about. We will update you as things progress.

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 Dr Martina Rodie, Liz Dougan, and Shannon McMullen. We have had a number of zoom events with some excellent speakers during the last 18 months. There is a whole series of webinars available all well worth watching:
https://officeforrareconditions.org/glasgow-webinar-series-in-rare-conditions/

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

www.facebook.com/ORCGlasgow. https://twitter.com/ORCGlasgow

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**

Emily Seymour *(Social Media Representative)* • email **Emily@tsssuk.org.uk**

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Thank you to all contributors to the Spring/Summer 2022 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 1st August 2022.

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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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