VOLUME 6: ISSUE 26: SPRING/SUMMER 2023

AspecTS

Charity Reg No. 1080507 Scottish Charity No. SC037932

Say hello to your TSSS Committee members...

...and to Holly, the newest (and cutest) member of our Chairs' family!

TS Awareness Day
21st June - see page 7

TURNER SYNDROME SUPPORT SOCIETY NEWSLETTER

Editor's Message

Hi and welcome to the latest edition of AspecTS.

Spring is here, even if it hasn't felt much like it, but it's great to be able to get out and about again and enjoy the fresh air.

We look forward to some big events over the next few months for our members

A couple of weddings on the horizon and the first Conference in three years in September and, of course, the Eurovision Song Contest here in Liverpool.

Hopefully the sun will appear soon and our new Nanna and Grandad, Susie and Steve, can get out in the sunshine with the pram. Congratulations to them and of course, the proud parents, Melissa and Mark.

We have added a competition page to the latest edition, please let us know if you like it.

Please send in your stories of your first experience of Conference (no more than 500 words please) and let everyone who hasn't been know what the experience is like. We will publish as many as we can over the next few editions.

Many thanks to all our contributors, please keep your thoughts and articles coming in. Any suggestions for anything else you would like to see in Aspects please let us know.

We hope to have a second-hand (or is it now pre-loved?) bookstall at the Conference to raise funds. Please keep the books you no longer want and bring them along to conference to donate, we are particularly short of children's books.

Don't forget to book early for conference to ensure that you get a place and the best price, hope to see you there.

Phil, Maggie and Ellie

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Please remember to renew your membership – see page 6

Chair's Report

Hi everyone

I hope you are all doing ok.
I have exciting news for you all. I am a Nanny at last. Melissa had a gorgeous baby girl on 13 Feb. Her name is Holly Jayne and she weighed 9lb 5oz. Melissa, Mark and Holly are staying with us for a few months. Mark is in the process of building a house for them all but it won't be ready until the summer. At least I will see Holly everyday which is just so lovely. She is just a wee princess in my eyes. She slept through the night from day 1 so Melissa is getting a good night's sleep. I am in "Nanny Heaven" right now.

The next best thing happening this year is that Geoff and Jasmine are getting married on 2nd June. I can't believe how quickly it has come round as they booked their wedding about two years ago.

No doubt you will all know about this year's conference. That's it booked now. Now is the time to book your place. This year it is in a different venue which we think everyone will like. It took a lot of time finding a venue that can cater for all our needs. I am so looking forward to this year's conference and to have a catch up with all you lovely people. It has been so long since we have been together so it will be a big party for us all. The only thing is .....wait for it .....there will be no "chips" getting cooked for us at 1/2am!!!! I am so gutted.....

We have a new addition to the family apart from Holly. We have adopted a blonde coloured Lurcher. It has been a hard few months with Bailey but she has turned a corner for the better. She is a Romanian dog but came to the UK when she was 5 months old, she is now 2 but she had a tough time. She nearly went back to the Rescue place. We got her a calming collar which works with the contact of it on her skin. Also, she has a collar that if she is bad, we have a remote that buzzes or it sprays lemon which stops her immediately. She doesn't like our door bell and my ring tones on my phone, she just barks so badly, she is just so stressed. Also, would you believe she won't turn left when we take her a walk. Some days we can't even get her outside our gate, she is just so skitty with outside noises, she jumps when she hears a bang or other noises.

Today she escaped and I spent 15 minutes up and down the street shouting for her. A nice lady had her in her garden. So off we went home, she went through the front door and then out the kitchen door and ESCAPED AGAIN. No sooner had I used my inhaler when I had to go look for her. Well, she zoomed past me about 4 times thinking it was a blooming game when another lady managed to catch her. Needless to say, she didn't need her walk today. She has been in her bed all day and I have been using my inhaler all day ha ha.

I will end now as my "nanny duties" are required. Melissa and Holly will be coming to Conference so you will be able to have a cuddle with her.

Mrs TSSSxxx

Holly

Bailey

Arlene's Report

I hope this newsletter finds you all safe and well.

We had a difficult end to 2022 lots of mixed emotions. My cousin sadly passed away, quickly followed by my Mum. She had been in a lot of pain and although we feel her loss greatly, we take comfort in that she is no longer in pain. Plus, I had a lovely 60th birthday thanks to everyone for their kind wishes, lovely cards, gifts, and donations to the TSSS. Your kindness is very much appreciated. I had a wonderful boost when some of my TSSS friends came to Harrogate when I was there at the BES Conference. I got a wonderful surprise when Susie came to my family dinner in Glasgow. I am so lucky to have such wonderful friends. We are all well and looking forward to a spring and summer full of hens, stags, weddings and celebrations. It is so nice to have events to look forward to.

Please forgive the delay in sending this newsletter. It has been a busy time getting everything ready for our conference. We can't wait to see you all again at our wonderful new venue. Please read through all the information we have provided for you. Hopefully it will answer your questions, if not we are only a call or email away. After such a difficult few years, it is good to have conference 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. If you are struggling and want a chat do give me a ring on 07947 554587 and 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 as it is very different. At conference we will introduce it to you in more details and hope to have volunteers to help you log in and check your data is accurate.

The committee have continued to work hard and had many meetings over zoom in the last few years. We did finally manage to meet in person in January to work on the conference and the plans for this year. It was brilliant being together again and bouncing ideas and suggestions about.

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.

Take care and stay safe.
Best wishes

Lady Arlene x

Important Dates 2023

TS Awareness Day
21st June 2023

Cardiff Awareness Open Day
24th June 2023 (Venue tbc)

International Growth Awareness Day
20th September 2023

TSSS Conference
22nd to 24th September 2023 – Yarnfield Conference Centre

Arlene's Diary Dates

Clinical Updates
24 - 26th April 2023 • Birmingham

ECE 21st -24th May 2023
Turkey (unable to attend)

ESPE 21st-23rd September 2023
The Hague (unable to attend)

BSPED 8th to 10th November 2023
Manchester

BES 13th to 15th November 2023
Glasgow

Aortic Dissection Trust

The Aortic Dissection Trust is raising awareness about Aortic Dissection and hope to work together in future, helping to raise awareness. They have a new animated health sketch explaining aortic dissection do have a look at their website.
https://aorticdissectioncharitabletrust.org/

GDPR

We ask that to attend conference you are an up-to-date member of the TSSS. If you are a member, you will be paying a monthly or annual payment to us, having completed the GDPR survey to activate your membership. This gives us all the consent and information we need to introduce you to other families.

Masters & Ambassador Awards

Don't forget to send your nominations in for the awards this year. Winners will be presented at conference.

Details are on the website **https://tss.org.uk/about/awards**

Some previous Masters Award winners:

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.

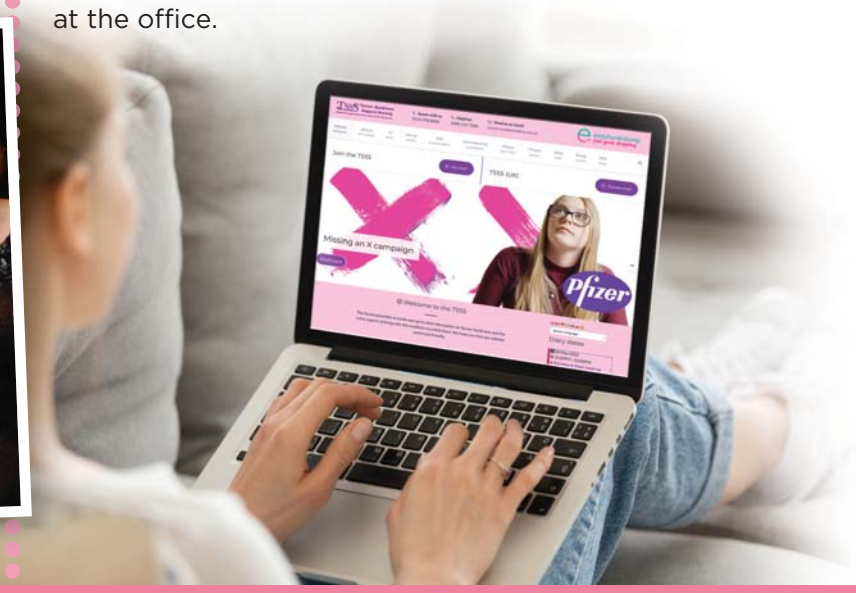
If you are paying by standing order (annual £30 or monthly £2.50) please check with your bank that your fees are up to date. Thank you for your continued support.

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 into 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.

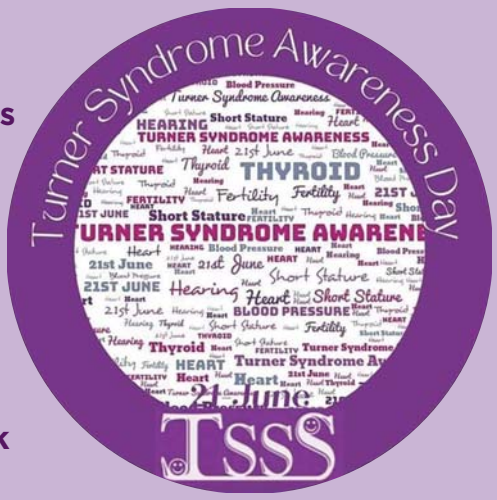
If you are a long-standing member, please ensure you have completed the GDPR survey to consent to staying on our database. If you are not sure if you have done it already, please do it again **https://www.surveymonkey.co.uk/r/TSSS-Membership**. If we do not have your consent, we will have no choice but 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)
If you have any questions or need help completing the survey, please do not hesitate to contact Carlene or Arlene at the office.



TS Awareness Day 21st June 2023

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.



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

This year for TS Awareness Day, 21st 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, 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://www.facebook.com/arlene.smyth15/

https://twitter.com/TurnerSyndSoc

https://twitter.com/TSSSARLENE

TSSS Instagram
@tsssukofficial
@astsssuk12

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

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

Emma Woods Fundraising Update

Debbie, Emma's Mum, and friends are again doing a Trek for TS. Thank you so much ladies and good luck with the training.

https://www.justgiving.com/fundraising/deborah-woods6?utm_source=copyLink&utm_medium=fundraising&utm_content=deborah-woods6&utm_campaign=pfp-share&utm_term=bddcf76792894286bfe77a15cedd989e

Cliona Robertson has set up a page in memory of Emma. Thank you so much and good luck.

https://www.justgiving.com/fundraising/cliona-robertson3?utm_source=copyLink&utm_medium=fundraising&utm_content=cliona-robertson3&utm_campaign=pfp-share&utm_term=04822a5c2ed540a7987a8e9fef6d5cd8

Lily Tyson

Our lovely Lily Tyson has set herself another fundraising challenge for this year. Unfortunately, Lily is due to have eye surgery this year, so she is not going manage to complete her challenges herself.

So, her dad Chris, family, friends, and her dad's work colleagues have agreed to complete a variety of challenges on Lily's behalf. They are doing marathons, bake sales, coffee mornings etc throughout this year. If you would like to support Lily, you can by following this link: **https://www.justgiving.com/team/lilysletsgoteamchallenge**

Lily and Chris conquered Snowdon on last year's challenge!

Mental health and neurodevelopment in children and adolescents with Turner Syndrome

The SOAR study aimed to improve our understanding of the behaviour, development and wellbeing of girls and women with Turner Syndrome. Most research into Turner Syndrome is focused on physical health. Our aim was to find out more about wellbeing and behaviour.

127 girls aged 5 to 19 and their parents took part in the study by filling out questionnaires. We found that one in 10 girls met criteria for an anxiety disorder. We also found that most girls had experienced significant social communication difficulties and nearly one in four met diagnostic criteria for autism. Overall, one third of girls met criteria for a diagnosable mental health or neurodevelopmental condition (e.g. autism or ADHD).

With your help we conducted the largest survey of children and young people's mental health in Turner Syndrome – a huge thank you to everyone who took part!

If you want to find out more, the published article is available here:
https://journals.sagepub.com/doi/full/10.1177/1745505721133635

Dr Jeanne Wolstencroft

Thank you for involving the TSSS in your research and we appreciate your continued support.

International Conference

As much as it breaks my heart, we have agreed we can no longer host an International Conference.

This is for many reasons, such as international travel 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 is important to protect the society from any financial risk and therefore we cannot take any risks. We worked on the International Conference for 4 years, planning and organising, then Covid hit and spoiled it all.

We will begin a call for bids to host the next International Conference and see if any other country is willing to host. We will of course offer them as much help and support as they need.

Thanks to some support from the Global Novo Nordisk team, we are planning 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, followed by a day for the TS families. I am not sure exactly when that will be. We are hoping for late 2023 or Spring 2024.

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

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 member of the TSSS. 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**

Patron announcement

It is with great pleasure that we announce that both Prof Melanie Davies and Prof Gerry Conway from UCLH London, have kindly confirmed that they will be delighted to take on the role of Patron. As you know they have both shown their commitment to Turner Syndrome and the TSSS over many years. We felt that it was time that we acknowledge their support in a formal way. They will also co-chair our medical advisory board. We are currently gathering up-to-date details and photos of all the board members and will put them on the website and they will be displayed at conference.

Patron of Turner Syndrome Support Society [UK]

Turner Syndrome Support Society [UK] Clinical Advisory Board

Professor Melanie Davies is a consultant obstetrician and gynaecologist and accredited subspecialist in reproductive medicine, senior consultant at the Reproductive Medicine Unit, and chair of trustees of the EGA Hospital Charity.

Her special interests are in gynae-endocrinology and fertility preservation. Specialities include, Reproductive endocrinology, Menopause and premature menopause (POI), Reproductive effects of cancer, Polycystic ovarian syndrome, Turner syndrome & Care of adolescents and young adults.

Melanie runs a large service for reproductive effects of cancer and chronic disease and leads dedicated clinics for women with premature ovarian insufficiency and adolescent care. She set up and leads an NHS 'emergency service' for women with a new cancer diagnosis to offer fertility preservation.

Melanie is the founding chair of Fertility Preservation UK and has been a member of the medical advisory committee of the British Menopause Society and the executive committee of the British Fertility Society. She was previously responsible for the HFEA-licensed fertility services provided at UCLH, a clinical advisor to the HFEA and a contributor to NICE guidance on fertility, menopause, endometriosis, and heavy menstrual bleeding.

NHS and Academic Posts

Consultant Obstetrician and Gynaecologist, University College London Hospitals. Professor of Reproductive Medicine, University College London

Articles & Videos

Professor Davies is actively involved in research and training. She is the chief investigator for the POISE study, a multicentre NIHR-funded trial on treatment of premature menopause (POI), and the BLUSH study which looks at non-hormonal treatments for menopause symptoms. She lectures nationally and internationally and has publications in the New England Journal of Medicine, British Medical Journal, and Human Reproduction. She is an experienced RCOG training programme director for reproductive medicine and has chaired the national subspecialty training committee.

Patron of Turner Syndrome Support Society [UK]

Turner Syndrome Support Society [UK] Clinical Advisory Board

Professor Gerard Conway is a retired consultant endocrinologist at University College London Hospitals and Professor of Clinical Medicine in the Institute for Women's Heath, University College London. His clinical practice covers general endocrinology including pituitary, adrenal, thyroid and reproductive endocrinology.

His clinical research interests are in the field of reproductive endocrinology particularly polycystic ovary syndrome, ovarian and testicular function, disorders of sexual development and Turner Syndrome. This research has formed the basis of over 160 academic publications. Professor Conway maintains a clinical research program with visiting international research fellows.

Professor Conway qualified from the Royal London Hospital in 1981 and trained in Diabetes, Endocrinology and General Medicine in several centres in central London. His research thesis was in the endocrinology of the polycystic ovary syndrome, and he then undertook as fellowship in genetic research in Prince Henry's Institute for Medical Research, Melbourne Australia. On return he became Senior Lecturer in Medicine at UCL in 1994 and subsequently Professor of Clinical Medicine in the Institute for Women's Heath UCL in 2012.

With a major interest in teaching, Professor Conway lectures in Reproductive Endocrinology, for the Society for Endocrinology, the Royal College of Obstetricians and Gynaecologists and internationally with the endocrine societies in the USA, Sri Lanka, India, New Zealand, Australia, Japan and throughout Europe.

Patient care is at the heart of the clinical work of Professor Conway and he works closely with many patient support groups.

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
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
Caroline Cooper • 07966 645255
cazhoward73@hotmail.com
or Ruth Whittington • 07793 744509
ruthmwhittington@hotmail.com

Kent Friendship Group
Robyne Winstanley • 07979 410422
robynewinstanley@live.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
tam.richards1976@gmail.com

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

Isle of Man

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

Wales

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

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

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

Ireland

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

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

Scotland

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

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

Central England Friendship Group Christmas Party 2023

The party is back after 3 long, difficult years – save the date!!

Sunday 3rd December 2023
2.00 pm – 4.30 pm

St Peters Church Hall,
Holly Lane, Balsall Common,
West Midlands CV7 7EA

This is a social event for all to catch up and have fun at Christmas, all are welcome including extended family and friends. There will be a disco for the children, raffle, sandwiches, crisps, cakes etc, so for me to organise the catering can you all please let me know if you are coming, how many will be in your party and the names and ages of any young children?

In previous years the event has been funded by myself and a couple of other members but with the rising costs, unfortunately, this year, I am going to have to ask for a small donation towards the event.

If you require any further information, please do not hesitate to contact me.

Hope to see you all there.

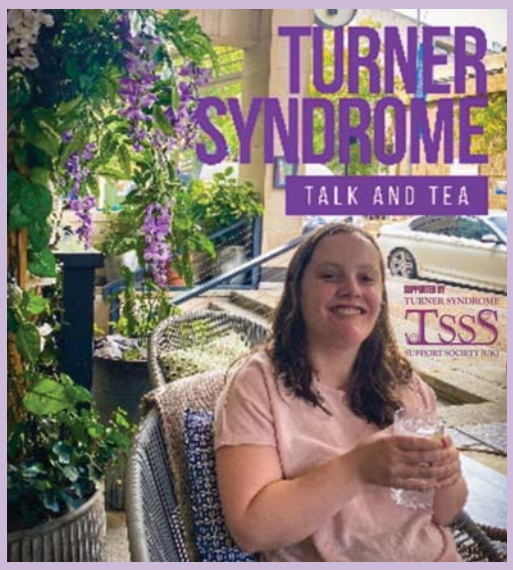
Jackie

Tel: **07977 486898**
Email: **shonaemily@aol.com**

Turners, Talk and Tea

Podcast Update

Turners, Talk and Tea has had 12,500 plays altogether. Over 100 episodes and it still feels just as exciting as when I first started my podcast.



It really does mean a lot to me that this podcast has been, and is continuing to be, received so well. It's now a global podcast, being played in 45 countries and I'm only 7 states away from being played in all 52 states of America, which is mental.

One really eye-opening episode for me was when I was talking to Beth (and I really like having these deep conversations although they make me a bit uncomfortable) purely because of some of the upsetting/deeper conversations, I think, are really needed and hopefully they are helping people feel less alone.

For me volunteering has given me such a sense of purpose and belonging especially within the TSSS. It has given me such newfound different respect for how much everyone one works behind the scenes. The great thing about volunteering for TSSS is that no matter how little you volunteer everything is valuable. I really, really encourage people to volunteer for the Society, especially at conference as it's such a big event and the more volunteers the smoother things will be. If you would like to be on my podcast message me at:

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

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

Or my email is **emily@tss.org.uk**

Thank you to everyone for your support and nice comments on my podcast. It really does mean a lot to me 💜

Emily x

Thanks, Emily, for the wonderful job you are doing with the Podcasts, they really do help a lot of people. ***Arlene***

Missing an X Campaign

The TSSS is delighted with the continued success of a new website and social media campaign called #Missing an X www.missinganx.com

Facebook **https://www.facebook.com/missinganx/**

You Tube **https://www.youtube.com/watch?v=rXAR5nqXDkQ**

Instagram **https://www.instagram.com/missinganx/**

Watch the video made by some of our beautiful, amazing and talented members, who kindly gave their time and support to this campaign. Read the resource pack and please take into your schools. Help us spread the word via all forms of social media we want to get **#MissinganX #TSSSUK** all trending. The TSSS would like to thank our members and Pfizer for their support in this campaign.

This campaign has exceeded our wildest dreams with a reach of...

6,000,000 impressions
(views of posts/content)

2,000,000 reach

880,000 video views

90,000 web visits

1,000+ downloads

Let's work together to find thehundreds of girls and women with Turner Syndrome, get diagnosed and benefit from the treatments available, so that they too can live a healthy fulfilling life. So if you know a short girl, remember, although cute, may have a health related cause. Always worth getting it checked out.

My missing piece of X

Ever since I learnt of your disappearance, I have been searching for you; you were in my thoughts, my heart and soul.

I wondered if you were hiding in my school lessons; or perhaps on top of the climbing wall; with the rope in my hands, feet and hands steady, I climb up to find out.

When dancing I was searching, when singing and even whilst playing a piece of Einaudi.

I ran the distance in the hope you were waiting for me in the forest, where the birds were chirping in the trees.

I still keep on searching, rain or shine.

Perhaps I'll find you in my friendships, in the small talk and the conversations which go deeper.

You are everywhere and nowhere at the same time.

No one knows how much you are missed, but how can I miss you when you were never there to begin with?

And, deep down, I know I'll never find you.
Yet, perhaps I never needed you, because you were never there, I'm enough without you there.

Where ever you may be, I hope you're happy.

So, I give a warm embrace to my little missing piece of X.

Thanks to one of our members, Lula, for this thoughtful poem

Important update regarding Norditropin®

We have been contacted by the Novo Nordisk team who wanted us to share that there is and will continue to be a supply issue over the coming months with their Growth Hormone, Norditropin®.

The advice is to check your current supply of Norditropin® and update your homecare or hospital provider of current stock levels. If you have sufficient supply, no action is needed. Your hospital team are working on patient specific solutions for those with low or no supply of Growth Hormone. Please only contact your Health Care Professional for further advice if needed or are running low on your Growth Hormone supply. You can call your Paediatric Endocrinologist's Secretary, Endocrine Nurse Specialist or Home Care team who are aware of the issues and can advise on patient specific solutions.

Please rest assured that Novo Nordisk is doing everything they can to improve the situation and will keep us updated.

TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

Child Growth Foundation

If you are concerned, you are welcome to contact the TSSS on 0141 952 8006 or 07947 554587 or email turner.syndrome@tss.org.uk

The CGF support line is available if you have any concerns you would like to discuss with us on **0208 995 0257** and at **info@childgrowthfoundation.org**

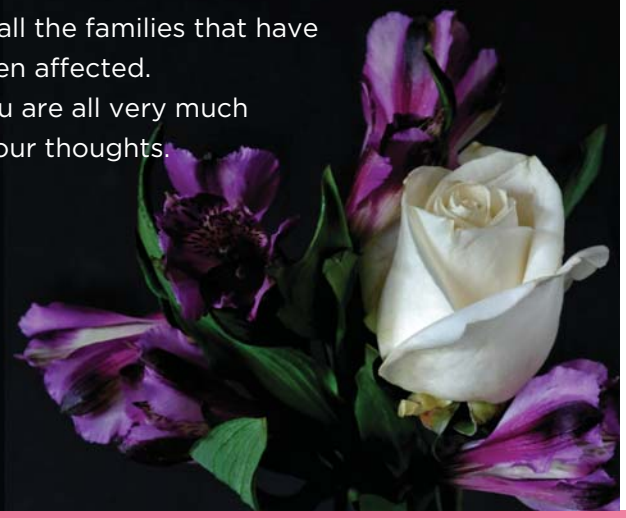
OUR CONDOLENCES

It is with a heavy heart that I share with you that our wonderful member Arthur Perkins has passed away.

He was an amazing father to the lovely Naomi.
If you have attended conference, you will have seen Arthur, he attended every conference with Naomi and joined in the male sessions. I feel so privileged to have known him, he was a true gentleman with a great sense of humour. Arthur was so proud of Naomi and all she has achieved. Naomi was a wonderful caring daughter to Arthur. I just love this photo of them both at conference a few years ago. Our sincere condolences and sympathy to Naomi and family. We are thinking of you and sending you love and strength.

Our condolences to the wonderful families who asked for donations to the TSSS in lieu of flowers at their loved one's funeral. Thank you for thinking of the TSSS at such a difficult time.

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.



TSSS Conference 2023
Booking information

The TSSS is delighted to welcome its members to our new conference venue for our annual conference and AGM over the weekend of the 22nd to 24th of September 2023. We are so excited to have found this new venue and we hope you like it. There will be some changes, but we have worked hard to ensure all our favourite things can still take place.

Yarnfield Conference Centre Yarnfield, Stone, Staffordshire ST15 0NL
Tel **+44(0) 1785 762605**. Details can be found at their website: **https://www.yarnfieldpark.com/** There is a great video and extensive photo gallery that will help you get a feel for the venue.

We are looking forward to seeing you all at conference after such a long gap because of covid. Thank you to all our amazing members, your continued support over such difficult times has made such a difference. The following information will hopefully answer all the questions you may have about the Conference and the venue. If not, please call Arlene or Carlene on **0141 952 8006** or E-mail at **turner.syndrome@tss.org.uk** and they will be happy to help.

Yarnfield has good transport links it is just off the M6 motorway, an hour from Manchester, Liverpool and East Midlands airport. The local train station is Stone, but Stafford and Stoke on Trent are large stations not too far away. We will have details on how to book and share taxis nearer the time from train stations.

Full conference details are on the conference page on our website. Updates will be posted on the website **https://tss.org.uk/about/conference** as and when they become available.

To book your place follow this link **https://www.eventbrite.co.uk/e/turner-syndrome-support-society-uk-conference-22nd-to-24th-september-2023-tickets-527736202187** to our Eventbrite link and complete the booking form answering all the questions asked. Don't forget to add on the optional extras, such as kids' & teens' club and any other extras available. If you need help, please call the TSSS office, we are happy to help.

We also have a 'Conference 2023' Facebook page **https://www.facebook.com/groups/730131058517047** where we will post information, photos and answer any questions you may have.

TSSS Conference 2023 Booking Terms and Conditions

You must be an up-to-date member of the TSSS, please check that you renewed your membership on the 1st of June 2023. This is for the data protection of all delegates attending.

If your membership of the TSSS has lapsed, you can update it via this link **https://tss.enthuse.com/membership#!/** it is £2.50 per month or £30 per year by direct debit through our membership platform Enthuse.

All conference bookings are made via the Eventbrite platform and payments are non-refundable.

Accommodation requests will be allocated wherever possible but, cannot be guaranteed.

It is highly recommended that travel insurance is taken out at the time of booking.

Yarnfield Conference Centre has plenty of open space outside and almost all rooms have natural daylight and have windows that can be opened for additional ventilation. The staff are friendly and helpful. Children are made to feel welcome and there is a lot of space for them to run around in. **Yarnfield is a cashless centre and only card payments are accepted.**

The accommodation is 4 blocks just outside the conference centre, a short walk under a well-lit covered path. The rooms are double en-suite, and some can be made twin beds (subject to availability. A cot or folding bed can be provided for children (subject to availability) Depending on the age of the children and family size it may have to be a parent and child in one room and parent and child next door. It is our intention to have family corridors, so families are together. Teen corridors so that teens can be next door to each other. Likewise for the Ladies with TS. We have plenty of rooms available to us, so we have room to grow. Please note it is not a hotel, it is a conference centre so there are some differences such as there is no swimming pool, the bar hours are set, no food once the restaurant is closed. There are vending machines and snacks available at the bar.

The conference price is based on a 48-hour all-inclusive rate. Starting with dinner and bed on Friday, Breakfast, Lunch, Dinner, and bed on Saturday with breakfast and lunch on Sunday.

Conference registration will be booked and paid to the TSSS [UK] via Eventbrite. The venue will allocate the rooms so please complete as much detail as possible on the booking form. We hope to have booking open ASAP at the latest 1st of

February 2023. Your registration pays for room & equipment hire, refreshments, snacks, meals, accommodation plus DJ, speakers & volunteer expenses we spread this equally across each delegate. We hope to offer a daily delegate rate for local families.

Estimated costs are £180 - £220 per adult (13 plus) and £90 - £110 for a child of 6-13 years and 0-5 yrs. – Free of Charge. There will be an additional £30 per person for kids and teen club this covers the crafts, activities, entertainers, and volunteer expenses. We have managed to keep the price to 2019 prices at ParkHall which in the current climate is excellent.

Details will be posted on the website **https://tss.org.uk/about/conference** as and when they become available.

TSSS Website

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

Do not 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.

You Tube

YouTube

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, expressed 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.

Instagram

@tsssukofficial
@astsssuk12

Twitter

@TurnerSyndSoc
@TSSSARLENE

TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

TSSS Facebook Group

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*. This is where you can share posts from. See other useful groups that we have liked.

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**.

Our public page now allows private closed groups, so I am moving all groups over.

Dear Friends

I would like to invite any member of this group **TSSS [UK] - Official Turner Syndrome Support Society (UK) https://www.facebook.com/groups/284339039660** that is a **UK RESIDENT** to join our new group that is part of our public page. **Turner Syndrome Support Society UK ONLY OFFICIAL (https://www.facebook.com/groups/1441009422955611)**

It is still a private group and only for UK residents. so that we can supply accurate information about the NHS and UK healthcare. It is our intention to move everyone over to this new group as soon as possible. **You must answer all questions and agree to all the rules to be accepted.**

We have also set up a group for all our international friends so that we can continue to share our comments with them and hear about their countries. **TSSS UK OFFICIAL INTERNATIONAL FRIENDSHIP GROUP https://www.facebook.com/groups/202255301407314**

This group is open to all who answer the questions and accept the rules.

The reason for the change is to move the groups over from my personal page to our professional page as Facebook/Meta now allows this to happen. Both groups will continue to be private groups.

IMPORTANT UPDATE

If you have requested to join our public page, new private groups and have not yet been approved, I am sorry for the delay in accepting you. The reason is often that we have noted that the rules section and the UK area have not been completed in full, therefore, we cannot accept the application.

Please **resubmit your request, having answered all questions without exception, or we cannot accept you.**

Regrettably, I have had to decline your requests, this will allow you to reapply. We look forward to receiving your completed requests.

See more information below.

Thank you so much for your patience.

Friendship Groups will all be moved over in due course.

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 on Facebook, it is important that **just because I may be a member of a group it does not make it part of the TSSS**.

The Turner Syndrome Support Society Member-only groups are given priority, if you have paid your membership and are not yet on the member only groups, please 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 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 is currently reviewing and updating our policy.

Fundraising News...

Give It Up, Give It In Appeal and Easyfundraising

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

We appreciate times are especially hard 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 Fundraisers, we raised **£478.51** from October 2022 to March 2023. Every penny helps thank you all so much. Keep up the good work!

Sadly, Amazon Smile has closed which is very disappointing. At no cost to you, Amazon donated, from October 2022 to March 2023, **£421.52**. We will receive a final payment in May. Thank you all so much for using Amazon Smile. please register for Easy Fundraising if you have not already done so

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

Important update on Amazon Smile in 2023

We received this letter from Amazon Smile which we would like to share with you.

"We launched AmazonSmile to make it easier for customers to support their favourite charities. We were excited about the potential for the programme and the impact it could have for many charitable organisations. We want to thank you for your partnership during all these years.

After almost a decade of running AmazonSmile, we learned that with so many eligible organisations—more than 1 million globally—our ability to have an impact was often spread too thin.

We are writing to let you know that we have made plans to wind down AmazonSmile by February 20, 2023. Until this date, customer purchases made via AmazonSmile will continue to accrue funds for your charity as normal. To help charities like you plan ahead, we will also provide you with a one-time payment equivalent to six months of payments based on what you accrued in 2022 through this program. The timing of this final payment will be approximately 60 to 90 days after February 20, 2023. We hope that this will help minimise the impact that this decision might have."

We are very disappointed that Amazon have made this decision at such a difficult time for small charities. It is what it is and we will miss the donations.

So, please encourage all your family and friends to join Easy Fundraising.

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.

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**.

Fundraising *Stories...*

Hi, I'm Poppy.

I am autistic and was diagnosed with Turner Syndrome aged 5, I am 31 now.
I recently held a coffee afternoon and decided to raise money for the TSSS, not only to raise much-needed funding but also for awareness as not many people know about Turner Syndrome.

We had a great afternoon with lots of cakes and brews! We held a raffle for a delicious chocolate cake made by my younger sister.

We raised **£180** for butterflies everywhere.

Well done Poppy and thank you so much for all your hard work and kind donations.
Please thank all your supporters for us.

Lucy, with her daughter Ruby and her son Lenny, worked hard to make sandwiches and then sold them at their dad's work. Together they raised **£80** for the TSSS and **£70** for the Childrens Hospital.

Well done Lucy, Ruby & Lenny and thank you so much for all your hard work and kind donations. Please thank all your supporters for us.

Weather Lottery / Unity Lottery

We have fundraised via the weather lottery for many years now. Recently the weather lottery was taken over by Unity lottery. We noticed that many of the members did not transfer over. That may be that they can't afford it or just forgot. After discussion with the committee, we made the decision to stop the lottery. Therefore, if you have been taking part, please cancel your direct debit. As we will no longer benefit from it.

If you are in a position to continue to support us, or can afford to give us an extra couple of pounds a month, please consider our "Give it up Give it In Appeal", this method of donation gives us a steady income and help us make a real difference. We thank everyone who donates every month.

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

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/

A message from Laura

Hi everyone, my name is Laura...

...and I was diagnosed with TS when I was 7 but recently, I was diagnosed with a tumour in my head around a year ago, however most importantly I had surgery to remove it over 4 weeks ago, and it has been a whirlwind plus I couldn't have done it without the help from Arlene and Sam because I didn't have the best aftercare from the hospital due to the professor who was my surgeon, my recovery has been very. very rocky but I have managed like the strong butterflies we all are. A few days ago, I had a CT scan to see if the surgery was a success, and it was!

Hi Laura

Thank you for sharing your story. It shows how brave and strong you have been.

Shona meets His Royal Highness, The Duke of Edinburgh

On Wednesday 15th March 2023, His Royal Highness Prince Edward, The Duke of Edinburgh (Trustee of the DofE Scheme) visited Portland College as part of a two-day tour of the country visiting providers of the Duke of Edinburgh (DofE) Award Scheme.

Shona was lucky enough to meet the Prince and a conversation took place between the two. Unfortunately, I was unable to attend the event as the college was closed to the public during the visit. Shona is aiming to achieve her Silver Award this year and the Prince watched on as she demonstrated her new skills accessing the 7-metre climbing wall in the college's Woodland Adventure Zone. She is hoping to take part in her qualifying expedition in July near Carsington Water in the Peak District.

One enormously proud mum, Jackie

Brilliant, well done Shona and good luck in achieving your Silver Award.

TSSS Goodies

Please do take a look at the online Shop on the website **https://tss.org.uk/shop/NEW-c142353792**

We have recently updated the merchandise with T-shirts, running vests, Caps, Bags and more, you could do some shopping and help us at the same time.

We also have some info 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

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**

Competition Page

Word search

Hidden in here are ten words associated with TS. The letters are all in a straight line vertical, horizontal or diagonal, up or down.
Can you find them? Answers in the next edition.

B	E	C	R	T	Y	H	J	L	V	G	R
X	M	G	O	L	P	N	E	W	C	E	G
C	O	M	H	D	J	L	O	A	B	N	K
A	S	P	E	C	T	S	R	S	R	E	N
J	O	J	H	E	A	R	I	N	G	T	I
B	M	U	T	G	K	R	E	D	U	I	P
F	O	S	C	U	I	C	L	U	N	C	E
D	R	A	W	A	R	E	N	E	S	S	O
V	H	K	O	R	A	N	E	Z	N	B	D
K	C	O	N	F	E	R	E	N	C	E	T
X	M	C	I	R	W	A	B	R	I	R	O
A	F	R	I	E	N	D	S	H	I	P	S
B	J	L	N	G	Y	N	U	O	R	L	T

Find the TSSS bunny

Hidden somewhere in Aspects is the Easter bunny (🐇) can you find it? Answer in the next edition.

TSSS Awareness Day 21st June 2023

Help raise awareness by displaying the TSSS Logo in the funniest or remotest place.

Send us a picture of yourself with the TSSS logo (bag, t-shirt, hat, hoody etc.) in the funniest or remotest location, post it on Facebook and tag TSSS. The best picture will win a Goody bag.

TSSS Conference

Please send in your stories of your first experience of Conference (no more than 500 words please) and let everyone who hasn't been know what it's like. We will publish as many as we can over the next few editions.

What was Arlene saying in this picture?

The funniest answer will be published in the next edition and will win a Goodybag.

Email **Turner.Syndrome@tss.org.uk**
for the attention of ASPECTS Editor.

My thoughts on my infertility...

I don't remember what age I was when my mam told me that I was infertile. I do remember the exact moment she told me; I was devastated. Looking back, I think why was I devastated? At that age I could not comprehend what infertility meant for me. But maybe it was a mix of emotions and the feeling of being different somehow, maybe being told that I couldn't do something that others could.

I was told about infertility then I thought that I might be able to have IVF and have a pregnancy. For me, not being able to have a pregnancy is more upsetting than not having children. Because you can adopt, you can have a family, but you can't have that pregnancy if you are infertile. However, I have since been diagnosed with aortic dilatation which means that the pressure on the heart during pregnancy could make my heart rupture in childbirth, so IVF is not an option. I got so excited about the possibility of IVF, to then find out about the aortic dilatation was in a way going through the heartache again.

Subconsciously, I felt like I had lost respect for myself because I can't carry a baby. Women are respected for going through labour because of how intense and hard pregnancy and labour is (sometimes, not for everyone). I felt like because I lost this respect for myself, I hadn't gained it anywhere else. It made me feel less of a woman I suppose. I know people have these words, meanings, and phrases that they say things like, "Oh, you can adopt, or you can do surrogacy" and "It must be so hard for you." As well-meaning the people are who are saying those phrases, it doesn't change the physicality of the situation. So, at times - a lot of times actually - infertility has been like a big knot in my head. It's very, very confusing trying to make sense of it all. Because I was thinking 'why am I getting so upset over something that I don't even know that I truly want?'

There's been pregnancy and birth announcements that I've seen, and this is where the confusion came in, because I felt like I didn't want to be excluded and isolate myself from seeing these things. I especially wanted to be included with the birth announcements, because I thought, this is probably going to be the closest thing I'm going to get to a birth announcement for myself. So, I wanted to see these things. But at the same time, it is just that reminder. It's not our fault we are infertile - but it's not the rest of the world's fault either. That's where the anger came in, I kept on thinking, why should we have to be the bigger person, change our mindset because we didn't want infertility, infertility was just forced upon us.

From talking very openly I feel much freer and a lot less angry. A standout moment for me was when I was upset and talking to my mam at one point, she said to me, "I know it's so hard for you." This was very, very nice to hear because she understands how hard it is for me. It might sound contradictory to what I said about people and their phrases. However, I found it was a subtle shift from, "oh it must be so hard" to "I know it's so hard". It made me feel validated, it made me feel seen and it made me feel heard. Which honestly, are the three things I think a lot of people want.

I now realise that talking about infertility and my thoughts has helped me to gain clarity. It has helped me loosen the knot in my head, so it's not as confusing as it once was. In my situation I talk with a trained therapist, but I think that talking with anyone who knows and cares about you will be a great help. It's helped me gain a lot of clarity on things and to be more certain in my thoughts.

One of the biggest game changers for me in my way of thinking is, I realised that the label "infertility," was making me sadder than I actually was. And I think that's because society (in general, not the Turner Syndrome Support Society) places

these stories and expectations of how sad you should be. I was thinking society's expectations of how sad I should be was clouding my opinion of how I actually felt. Rightly so, you hear these stories in the media of people being so upset by infertility, they are just heartbroken. That's often the word used with infertility, heartbroken. And I'm not saying that these people cannot feel that way. But for me it got to the point where I was used to seeing and hearing this so often. I was putting this expectation on myself – to be heartbroken.

With an expectation for me to feel sad, I forgot that I could have my own opinion on how I could feel because I got so used to seeing so many other opinions. From me realising I'm not as sad as I thought I was about infertility, made me feel a bit guilty. I'm so glad I started therapy when I did, because I feel like maybe the anger could have turned into bitterness if I had not processed my emotions properly and deeply. I think that being open and talking has helped me gain control. In a situation out of your control, you can take back the control it has over you.

Every moment in life has meaning, both good and bad, but it's only ever the meaning you give it. And I know it sounds silly to say, but I forgot I could have my own opinion when it comes to infertility because it was clouded by expectations, news, and society. One really, helpful thing for me is just asking "why?" By asking why I have been able to think deeper and get to the root of what I am feeling, then from that I could make a change in my opinion if I felt I needed to.

"Infertility makes me upset."

"Why?"

"Because I can't have a pregnancy."

"Okay, why does that make you upset?"

"Because I feel like I've lost the respect from people."

I remember how miserable I was thinking about infertility. I hope that conversations like this can help other people feel a little bit lighter and a little bit freer, if they are in a place that I was about infertility as well.

From talking, the 2 biggest changes in belief for me are:

- I have taken control of my thoughts on infertility rather than let them control me.
- I can have my opinion and if I want to be angry or frustrated then I can be – but it will not control my life or thinking.

I hope that this article will help people to feel less alone, make people question their beliefs if they are in the same headspace I was in and to talk honestly/openly instead of bottling emotions up.

Everything I have said in this article is just my opinion, that's all it is. It doesn't make it right or wrong and it does not have to be your opinion if you don't want it to be.

At the age of 25, I truly don't know if I want a child. I don't know if I want a family. But I think this is perfectly fine.

Emily Seymour

Thanks so much Emily for sharing your thoughts.

If anybody else wishes to share their personal thoughts or experiences on this subject please send them in and we will do our best to publish them, as and when we can.

Donations List

November 2022 to March 2023

Our sincere thanks for each and every donation

November 2022

Michelle Davis decided to take part in Stoptober to raise money and awareness for TS on behalf of her daughter with TS, **Courtney**. She completed the challenge and raised **£225**, including Gift Aid, for our society.

Well done, Michelle!

We received a kind and generous donation from the **Edinburgh Telephone Choir** of **£400**. They had an event planned pre-covid to raise money and awareness for our society. At last they were able to hold the event in November. Thank you so much.

One of our lovely friends **Ken Scott**, from another support society, volunteers with Kilt Walk that is held annually in Scotland. They kindly donated **£50** to our society on his behalf.

Thanks Ken!

One of lovely ladies **Caroline Marquis** holds talks about TS and our society in her local area. From these events she has raised **£85**, including Gift Aid, for us.

December 2022

One of lovely mums, **Kay Phillips**, donated **£37.50**, including Gift Aid, to our society, in lieu of sending out Christmas cards.

We received a kind donation from **Robert Dimbleby** of **£45** including Gift Aid.

We received a **£275.10** anonymous donation to our society.

On of our newer families, the **Luckocks**, made a kind and generous donation of **£5,000** to our society in December. They hoped they would be able to get match funding for this donation and they got another **£10,000**! So, their total donation is **£15,000**, including Gift Aid!

They have future fundraising plans for the year to come as well.

Thank you so much this really helps in the current climate.

Paul Bond donated **£125**, including Gift Aid to our society to help us continue to help families who have daughters with TS.

Courtney Costigan kindly donated **£100** to our society.

Our lovely **Arlene** donated **£31.25**, including gift aid, in lieu of sending Christmas card this year.

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 **£1,250** including Gift Aid.

We received a kind donation of **£87.50**, including Gift Aid, from N**eil Gardener**.

January 2023

'My name is ***Roisin Miller*** *and my mother,* ***Jean Miller****, sadly passed away on the 19th December 2022, My mum was always trying to raise awareness for Turner Syndrome as her granddaughter was born with TS, she had set up a Facebook page and managed it for years, helping others with TS understand difficulties they had and reassured them and helped them. At her funeral, we thought it would be the right decision to make the proceeds of donations to Turner Syndrome, mum would have wanted that.'*

The family have donated **£254** in Jean's memory.

Robin Macmillan donated **£187.50**, including Gift Aid, to help us with all the work we do.

We received a kind and generous donation of **£200** in loving memory of **Doris Crowder**. Her family and friends made the donations at her funeral as Doris's great granddaughter has TS.

We received a kind donation of **£110** in loving memory of the late **Sandra Moore,** beloved sister to **Jennifer Jones**.

February 2023

We received a kind donation from the pupils and staff at **Pipers Corner School** in High Wycombe. They raised **£488.36** from a collection at the school.

One of our lovely young members, **Ruby Taylor**, and her brother, **Lenny**, raised **£100**, including Gift Aid, for our society. They made sandwiches at their daddy's work and they sold them to all the other offices to raise awareness and money for us. Well done, Ruby & Lenny! See page 21.

David Volante decided to take on a big challenge of running 7k a day for the month of February. David wanted to raise awareness and money in memory of his daughter who lost her fight to TS and didn't make into this world in March 2021.

David's friends and family have dug deep and, so far, have raised **£1,884.92**, including Gift Aid. His target is **£2,000** and he still could make it.

One of our members, **Poppy Lee**, hosted a coffee morning to raise awareness and money for our society. They raised **£180** for our society. Please see the story and picture on page 21 of the newsletter.

March 2023

We received a generous donation of **£600** in loving memory of the late **Gordon Foster**. The donations were made on behalf of his great granddaughter who has TS.

Thank you so much for all your kind and generous donations. You have not only raised vital funds in a difficult climate but also much needed awareness.

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 who 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 we do not always get the notifications. We do not want to miss anyone out.

Thank you so much to the following people that we have had notifications from:

Holly Daly, Arlene Smyth, Rebecca Readings, Joleen Murray, Neula O'Grady, Gypsy Pope, Alexa Brammer, Amelia Cross, Chris Howson, Ella Cockerill, Hillary MacDonald, Anj A Cubitt, Kathleen Goodwin, Paige Smith, Susan Wall, Michelle Drake, Kelsey Hannah, Talisha Niwas, Hayley Cleaver, Nikki Fawkes, Vanessa Norton and Chlo Ronan.

We are so pleased to say that **£1,766.64** has been raised between October 2022 and March 2023.

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

It's what we do...

This is an e-mail I received, recently and I wanted to share it with you. Taking calls from those families who are given a diagnosis of TS during pregnancy, are the most difficult for me.

I want to share accurate and helpful information with them. Sadly, not I or a midwife or a doctor can give them definite answers. Even when a girl with TS is born, you don't know how severely affected she will be. As there are so many ifs, buts and maybes it is so difficult for these families to know what to do, as many of you know from personal experience.

Many families feel a pressure to decide quickly about terminating their baby or continuing with the pregnancy, not knowing if their baby will survive the pregnancy. I always do my very best to provide all the information they need to make this very personal decision for their family. We often have long conversations; I answer all questions as openly and honestly as I can. We provide some wonderful information to support families and help them understand what impact TS has on a child, especially that girls are individual and there is a wide spectrum in TS. I ensure that they know the full spectrum and how their daughter may be affected.

Hello,

Last year my partner and I phoned your charity to seek advice following our daughters Turner's diagnosis. After being told we should terminate, we listened to the doctor's advice and booked the appointment.

After doing further research, we found your website and spoke to Arlene from TSS. Following the call, we decided to cancel the termination and spoke to a UK midwife (as we were overseas), who advised us to return to the UK and have further tests.

Following these tests, we were told our daughter didn't have Turner's, and if we had taken the initial advice, we would have terminated a healthy baby. We had our daughter in November 2022.

We would like to thank you for your help and advice during this difficult time. We donated to your charity last year and will continue to do so this year.

Thank you again!

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.

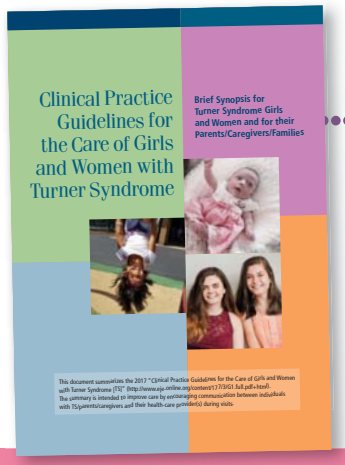
I was delighted to be able to attend this year's planning meeting in Florida. It was great to see everyone. So, interesting hearing about the different countries. The struggles and the successes they have to raise awareness and improve diagnosis across the world.

We will be taking part in International Growth Awareness sharing posts and photos across social media. This year we will raise awareness at our conference as it falls on the same week. 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. Don't forget to listen to Charlotte's story **https://morethanheight.com/en/life-with-growth-disorders/charlottes-story/**

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 continue to be a European Patient Advocacy Group (EPAG) even post Brexit. In January I was able to take part in the ERN EXCHANGE programme. We had an excellent few days learning and sharing good practice. I have learnt so much about registries, data and their importance. I have always believed in working with others. What is nice about ENDO ERN is you get to see it benefiting patients across Europe. Working side by side, dedicated doctors with specialist knowledge to share. I continue to learn from the many members and different countries involved. They also have some interesting webinars available, do have a look at their website **https://endo-ern.eu/**. I am so looking forward to the general assembly in April in Amsterdam. It will be the first time we have met since Covid.

EuRReCa

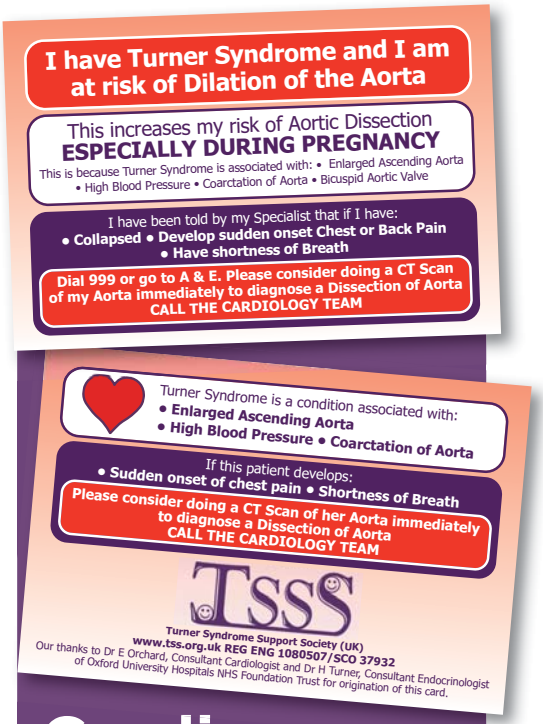
I am a proud member of the **EuRReCa** project. This is very exciting, working to create registries on Rare Conditions across Europe. I do enjoy taking part and learning from the others involved in the project. Do have a look at their website **https://eurreca.net/**

I am looking forward to speaking and sharing the patient's perspective at the EuRRECa conference in Leiden, Netherlands in April.

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 was created and is now live.

The I-TS website **http://i-turnersyndrome.org** will tell you all about it. Please do have a look at the patient information sheets and consent forms for TS so, if your doctor asks you to enroll, you will know what it is about. If you would like your data entered, please ask your doctor to add your data to the registry. The benefits of these registries will be invaluable to the future care of those with TS. Common themes will emerge, leading to new research being carried out in many different areas. So much potential for the future. We will update you as things progress.



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.

UK News...

The Office for Rare Conditions

Office for Rare Conditions Glasgow

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 was great for us to host a joint Xmas Party in December. The families came together, chatting with each other while the children had fun at a magic show. In the afternoon we had TS Information Talks and we very grateful to Dr Avril Mason, Sr Rosin Boyle, Dr Marie Freel and Dr Haytham Kubba who came along and answered everyone's questions. So good of them to give up their precious weekend time. We do hope you all enjoyed the time you had together catching up with old friends and meeting new ones. Our thanks to everyone who helped organise such a fantastic day.

It was just wonderful to be in the hospital atrium for Rare Disease Day what a great response we got from families. We met so many new families with rare conditions. The focus was on care co-ordination which is so important. Asking families about the number of hospital appointments and doctors they see was eyewatering. It is good to know that the Scottish Government are planning on improving care co-ordination in the future.

I would just like to thank all the volunteers, especially Ken who travelled so far to support us. Thank you to Liz, Shannon, Martina and Claire for all their hard work all year round but especially over Rare Disease Day. **Together we are stronger.**

"Hear hoofbeats? Think Zebras."

When teaching medical students in 1940, Theodore Woodward said: "When you hear the sound of hooves, think horses, not zebras."

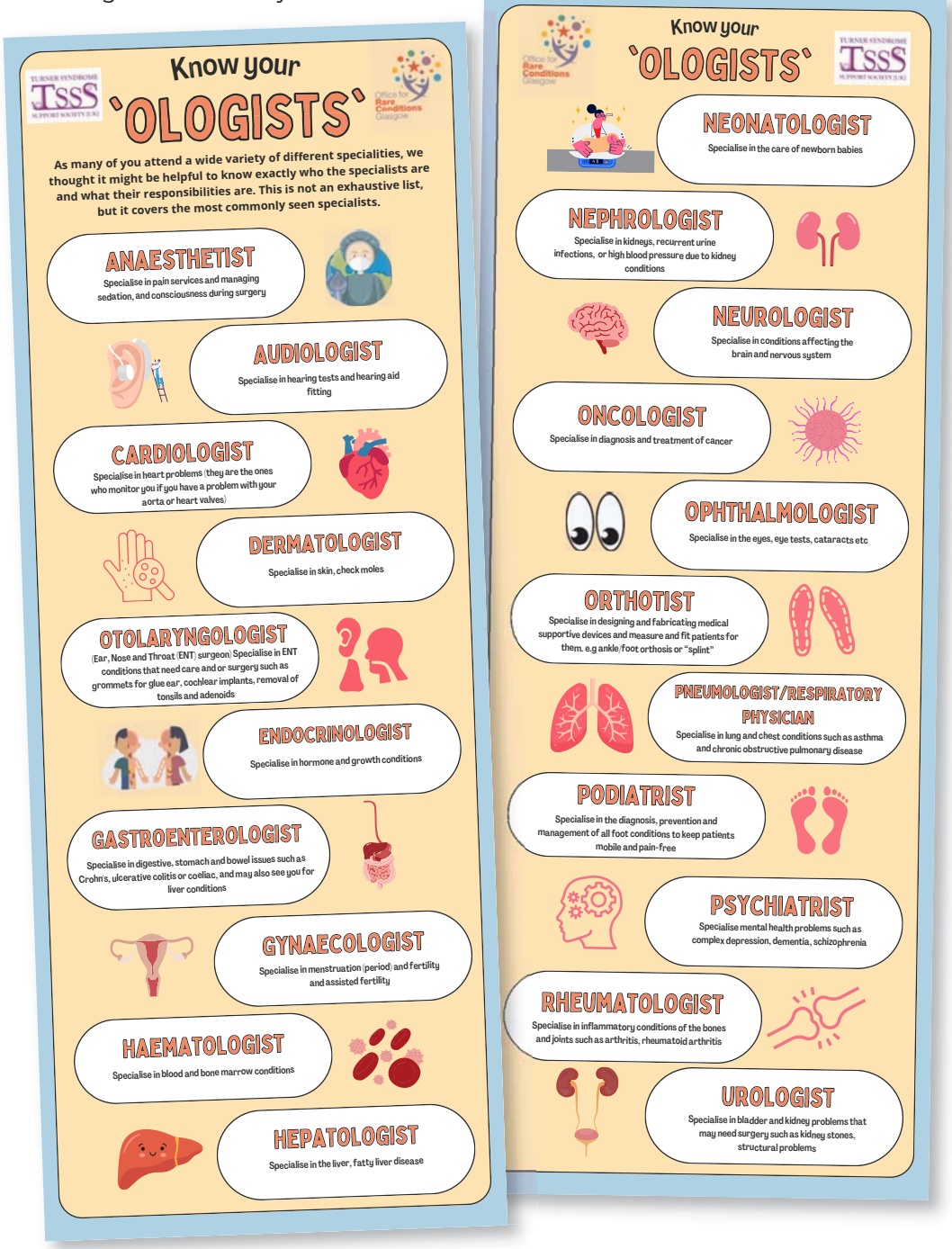
The term "zebra" is used for a rare condition. Dr Woodward was teaching his students to look for a horse or a 'common diagnosis' over a zebra – a rare condition.

Often people with rare conditions are mis-diagnosed, seeing one professional after another before they receive their diagnosis. This process can take a long time and can be very frustrating.

The rare disease community asks doctors to think of zebras, not just horses.

Know your Ologists!

As discussed at previous meeting we put together a list of various Ologists that we see. Shannon then worked some magic and produced a brilliant list for families. I have wanted to do this for families for such a long time. I am delighted it is finally out there.

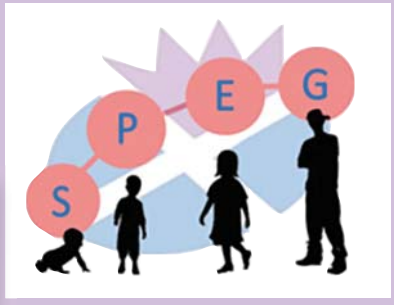


It has been very exciting, and a lot has been achieved in a short time thanks to Dr Martina Rodie, Liz Dougan, and Shannon McMullen. We have had a number of zoom events with some excellent speakers during the last 18 months. There is a whole series of webinars available all well worth watching: **https://officeforrareconditions.org/glasgow-webinar-series-in-rare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

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

www.facebook.com/ORCGlasgow

https://twitter.com/ORCGlasgow



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.

This year we finally met in person again and I was delighted to meet up with our friend Dr Malcolm Donaldson, he sends his best wishes to you all. Their website is **www.speg.scot.nhs.uk** if you want to have a look.

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 *(Mr & Mrs TSSS)* • Tel **07791 545747/ 07960 030162** • email **Susie@tsssuk.org.uk**

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

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

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

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

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

Thank you to all contributors to the Spring 2023 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 2023.

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Executive Officer

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