



Turner Syndrome Support Society [TSSS] 19th Annual Conference & AGM 11-13th of October 2019
Park Hall Hotel, Chorley, Lancashire, PR7 5LP

Welcome to the TSSS conference we hope you find the following information helpful and informative. If you have any questions please do not hesitate to ask any of our dedicated team of Trustees, Committee Members, Volunteers and Staff who are in a RED TSSS t-shirt/polo shirt or zippers.

We have put together an interesting and varied conference programme; we have had to make some changes due speaker's availability. We have a number of expert speakers and expert members who will share their knowledge in a variety of ways. Our experts will be available to you to answer questions and help you to make small changes that will improve your wellbeing.

We are sure there will be something for everyone. Our speakers this year are Prof David Skuse Child & Adolescent Psychiatry from Institute of Child Health London, Prof Gerry Conway Consultant Endocrinologist from UCLH London, Ms Melanie Davies Gynaecologist from UCLH London, Dr Helen Turner Consultant Endocrinologist Oxford, Dr Jo Blair Paediatric Endocrinologist in Alderhey, Liverpool, Antoinette Pimblett PHD Researcher at UCLH with Prof Conway, Matron Claire Goedhart is an experienced Nurse Specialist in London, Jeanne Wolstencroft PHD Researcher. Many of you already know Dr Gordon Watt affectionately known as "The TSSS Foot Man" retired senior lecturer in Podiatry at Caledonian University in Glasgow. As always we have the lovely Auntie Marian's who have talents in reflexology, massage and a whole lot more! We are having an International Panel session where members who have attended International conferences in the past will share their experiences with us, along with an update on TSI 2020 too. Another popular session is with David Marshall who has for many years now shared his experience on driving issues; he is a Disabled Aware Driving Instructor. We will launch our Driving Fact Sheet which David helped us with. We have some topic led sessions and solutions in the afternoon with many of our expert members. Members sharing their expertise this year are Arlene, Robina Wason, Dan Howarth. Our wonderful artistic director Sam assisted this year by Dan, Daisy, with Teen Co-coordinators Meg Cubitt, Ella Phillips & and teen reps Zoe Glasgow & our teen rep Grace McGowan. I am sure you will agree it is a wide and varied programme. Please note this programme is always subject to change.

We very much appreciate the support of all our speakers and volunteers. This year we are supported by Novo Nordisk Ltd, & Ferring Ltd we are very grateful for their support. Helping us deliver an informative enjoyable conference for all.

Those of you who have dietary requirements not met by the menu choices, please notify the TSSS registration desk in advance & the restaurant staff upon arrival at all meal times, thank you.

Please note all committee members and volunteers wearing red shirts are permitted to go to the head of the queue as their help is needed to run the conference.

For additional information please read your conference information guide available in your envelope at registration and on the website.

Our sincere thanks to all of our wonderful volunteers, committee members, trustees & staff for all their hard work your support is very much appreciated. Thank you to all the staff both front of house and in the background at Park hall Hotel for all their hard work over the weekend.

If you have a problem with your room please speak to hotel reception directly. If any issue is not then resolved please report to TSSS registration. Hotel room keys should be returned to reception by 10am on Sunday morning. Luggage can be stored in the rear of the Park Suite. Please store luggage safely and consider other members.

DRAFT CONFERENCE PROGRAMME AT A GLANCE 19th Annual Conference Sat 12th of Oct 2019
COLOUR CODE – Blue Open, Orange Parents, Red Ladies with TS, Senior Teens , Couples & Partners with TS, Team TeenS, Kids Club

If you have any questions? Please ask any of our volunteers in RED TSSS TOPS

PARK SUITE 9.00 – 9.30 9.30 – 10.00	<u>“ A year in the Life of TSSS” & “Missing an X but still Exceptional” Welcome</u> <u>Selfie & Raise your Bands photo then TEENS move to LANCASTRIAN</u> <u>Annual Report & AGM – ALL</u>					LANCASTRIAN Team TeenS 9.10 – 13.00	ECCLESTON KIDS CLUB 8.50 – 13.00
10.00 - 10.30	PARK SUITE – OPEN SESSION – Heart update & research opportunity Prof Bernard Keavney - Manchester					Welcome	
10.00 - 13.00	Rufford - Croston Suite - OPEN SESSION - Podiatrist Gordon Watt Foot for care & Auntie Marian’s for time out, a massage & more					Ice Breakers	Welcome
10.30 – 11.00 Tea & Coffee	Tea-Coffee is available in the Park Suite, Medieval Hall, Lilford Suite & Charnock Please make your way to your next session for tea & coffee.					Juice	Juice
	PARK SUITE OPEN - PARENTS	Medieval Hall Ladies with TS	LILFORD Ladies with TS	Charnock LADIES WITH TS ONLY	Rufford		
11.00 – 12.00	<u>Pubertal Induction/Transition</u> <i>Dr Melanie Davies Gynaecologist UCLH Dr Jo Blair Paediatric Endocrinologist - Alderhey</i>	<u>Health Checks Launch</u> <u>-Health & Wellbeing in TS</u> <i>Dr Helen Turner Endocrinologist- Oxford</i>	<u>Diabetes & TS</u> <i>Antoinette Pimblett MSc PHD Researcher UCLH London</i>	<u>Let’s talk about intimacy</u> <i>Matron Claire Goedhart Nurse Specialist London</i>	<u>Foot Care/ shoe buying</u> Informal talk/tips <i>Dr Gordon Watt Podiatrist Glasgow</i>	<u>Musical performance workshop</u> with Sam and her team of volunteers	Fun, games, crafts & lots more
12.00 - 13.00	<u>Making a good impression: Am I thinking what you’re thinking</u> - Update from the SPOT study and introducing the FACE study <i>Prof David Skuse –Psychiatrist</i>	<u>Liver, HRT, BP & more</u> <i>Prof Gerry Conway Endocrinologist UCLH</i>	<u>Growth, BP, & more</u> <i>Dr Jo Blair Paediatric Endocrinologist</i>	<u>Let’s talk about intimacy</u> Senior TEENS ONLY <i>Matron Claire Goedhart Nurse Specialist</i>	<u>Parbold</u> <u>Ask Arlene</u> Ask anything you want to know about TS	<u>Senior Teens to Charnock Junior Teens in Lancastrian</u>	
13.00 - 14.00	LANCASTRIAN - LUNCH FOR ALL – DANCE REHEARSAL – SEE BOARD FOR DETAILS						
14.00 – 14.30	PARK SUITE - TEA & COFFEE - TSSS GOODIES STALLS & Last Chance to Buy Raffle Tickets						
	PARK SUITE	MEDIEVAL	LILFORD	Charnock	Parbold		
14.30 – 15.30	<u>The science of making friends</u> Update from the SOAR study social skills training pilot <i>Jeanne Wolstencroft PHD Researcher- London</i>	<u>Mindfulness with Moya Fletcher</u> <u>Limited numbers You must book your place in advance</u> <i>A chance to learn about the benefits and try it out</i>	<u>Getting the most form your TS Clinic</u> <i>Arlene Smyth & Robina Wason with Prof Gerry Conway</i>	<u>Let’s be positive Parents</u> <i>Dale Vincent Life Coach</i>	<u>Partner’s Booklet Update & informal chat</u> <u>Susie & Stephen Wall</u>	14.30 -16.50 All teens in Lancastrian <u>A visit from community police to advise on keeping safe if available</u>	14.20 -16.50 PROMPT Pickup & before rehearsals
15.30 – 15.50 Tea & Coffee	PARK SUITE Tea & Coffee	MEDIEVAL Tea & Coffee	LILFORD Tea & Coffee	Charnock Tea & Coffee			Fun, games & dance rehearsals
15.50 – 16.50 FINAL SESSION	<u>TSI2020 UPDATE</u> International Stories Shared Arlene, Kylie, Susie, Stephen, Hayley, Caroline, Prof Gerry Conway	<u>Mindfulness Session</u> <u>Limited numbers You must book your place in advance</u> <i>A chance to learn about the benefits and try it out</i>	<u>Driving Tips</u> <u>David Marshall</u> <u>Fact sheet launch</u> <i>Helpful Hints with driving instructor</i>	<u>Let’s be positive Women</u> <i>Dale Vincent Life Coach</i>			
CLOSE 16.50 - Time to get dressed up for dinner & the show in the Lancastrian – Bar opens at 18.00 & Thomas will be there ready to take your photos							
Rehearsals 16.50 – 17.05 A final rehearsal in the Lancastrian if required see board for details							

Sunday 13th of October 2019 – TSSS Workshop Programme AT A GLANCE

Please sign up for workshops as soon as possible to help with allocation of rooms for each one, thank you.

COLOUR CODE – Dark Blue-Open, Red-Ladies with TS, Light Green-Team Teens, Purple-Kids Club, Orange-Mums, Light Brown-Female ONLY,

Brown-MALE, Dark Green-Mothers of Adults with TS, Pink-F/ship Group Leaders, Light Blue-Siblings

Kids Club Juice & biscuits		09.50 – 13.00 in the Eccleston Suite – TSSS Movies – A family film to relax after the late night or free play. 10.50 then get ready for “The Children’s Entertainer” at 11.30- 13.00				
Team Teens Tea & Juice Break		10.00 – 10.50 in the Medieval Hall – Mindfulness with Moya Fletcher 10.50 – 11.10. 11.10-12.00 Conference feedback, planning a heart to heart or both.				
Workshop 1	Workshop 2	Workshop 3	Workshop 4	Workshop 5	Workshop 6	Workshop 7
All Workshops are from 10.00 -10.50 with Coffee Break in the Park Suite, Lilford & Medieval Hall 10.50 -11.10						
Park Suite [100+]	Charnock Suite [40]UPSTAIRS	Lilford Suite [40]	Parbold [25]	Heskin [40] UPSTAIRS	Croston Suite [20]	Village Inn
<u>Heart to Heart Mums ONLY</u> <i>A chance to share thoughts with each other</i>	<u>Sibling Workshop Dan Howarth</u> <i>A chance to share thoughts with each other</i>	<u>Heart to Heart Over 35 Women with TS ONLY</u> <i>A chance to share thoughts with each other</i>	<u>Mums of Adults with TS ONLY</u> <i>A chance to share thoughts with each other</i>	<u>Heart to Heart Under 35 Women with TS ONLY</u> <i>A chance to share thoughts with each other</i>	<u>Craft & Chat Bring own craft Can continue until 12 noon</u> <i>Have a natter do some crafts</i>	<u>Dads /Partners Male Relatives ONLY</u> <u>Can continue until 12 noon</u> <i>Have your say or talk about sport</i>
Coffee Breaks in the Park Suite, Lilford & Medieval Hall 10.50 -11.10						
Workshop 8	Workshop 9	Workshop 10	Workshop 11	Workshop 12	Workshop 13	Workshop 14
All Workshops are from 11.10 -12.00						
Park Suite [100+]	Charnock Suite [40] UP STAIRS	Lilford Suite 40]	Parbold [25]	Heskin [40] UP STAIRS	Croston Suite [20]	Village Inn
<u>Heart to Heart Mums, women, & female relatives ONLY</u> <i>A chance to share thoughts with each other</i>	<u>Relationship Tips - 18 plus Ellie & Ella</u> <i>A chance to share experiences and tips for a dating fact sheet</i>	<u>Driving Tips David Marshall Fact sheet launch</u> <i>Helpful Hints with driving instructor Repeat from Saturday</i>	<u>Friendship Group Leaders Meeting</u> <i>Share ideas and support each other</i>	<u>Heart to Heart Mums, women, & female relatives ONLY</u> <i>A chance to share thoughts with each other</i>	<u>Craft & Chat Bring own craft Continued</u> <i>Have a natter do some crafts</i>	<u>Dads /Partners Male Relatives ONLY</u> <u>Can continue until 12 noon</u> <i>Have your say or talk about sport</i>
<u>12.00 – 13.00</u>	Final session in the Park Suite for all conference delegates, feedback, discussion about thoughts for the future					
<u>13.00 – 14.00</u>	Lunch is available to those who have booked, in the Lancastrian Suite					

Thank you for your company & have a safe journey home.

NOTES FROM TSSS CONFERENCE 2019