



Turner Syndrome International Conference 16th-20th July 2020 [TSI 2020]

Draft Conference Programme

The TSSS UK is looking forward to hosting the 10th Turner Syndrome International Conference [TSI 2020]. We are planning to have a varied programme with something to suit everyone, including lots of social time. We have invited some of the world's leading specialists on Turner Syndrome [TS] to share their expertise with us, and are very grateful to Novo Nordisk and Pfizer for sponsorship of this event.

Many of the speakers you suggested in the register of interest you completed will be attending. Prof Gerry Conway – Reproductive Endocrinologist and Ms Melanie Davies - Reproductive Specialist both from UCLH London will give the keynote presentation on Friday 17th July 2020.

Other speakers include a number of Paediatric Endocrinologists; Dr Philippe Backeljauw - Cincinnati, USA, Prof Paul Dimitri - Sheffield, UK, Prof Malcolm Donaldson - Brighton, UK, Prof Jan Lebl - Czech Republic and Dr Jennifer Law - USA.

Adult Endocrinologists include Dr Claus Gravholt – Denmark, Dr Helena Gleeson - Birmingham, UK and Dr Helen Turner – Oxford, UK.

Other specialities include Geneticist - Dr Chieko Tamura - Japan and Dr Ruth McGowan - Glasgow along with many other knowledgeable specialists on a wide range of topics related to TS.

A number of topic led workshops will be available each day. They will be led by a TS expert, in smaller groups. We will try and repeat some of these workshops to let you attend as many as possible. There will be workshops for women with TS, parents of daughters with TS, Teens with TS and partner's sessions (if attending). Some workshops will be open to all and others will be closed for a specific group e.g. Ladies with TS only or Parents only. This is to allow privacy and openness during the workshop. Topics have been selected from the responses to the register of interest.

We will have a photographer available to capture memories.

Further transport information will be on the website as soon as possible.

Please note the conference programme is subject to change and not confirmed yet.

We are delighted to tell you TSI 2020 Conference Registration is now open to book your place please go to <https://tsi2020.eventbrite.co.uk>

THURSDAY – STIRLING COURT HOTEL

09.00 - 17.30 - **“Meet the Expert Conference”** is open to all Health Care Professionals [HCP’s] interested in Turner Syndrome [TS]. This is an opportunity to learn from the Expert Specialists invited to speak at TSI 2020 conference.

To book your place, please follow this link.

<https://www.eventbrite.co.uk/e/turner-syndrome-international-meet-the-expert-education-day-tickets-92173680961>



Turner Syndrome International Conference [TSI 2020] 16th-20th July 2020 Draft Conference Programme

THURSDAY - STIRLING COURT HOTEL

14.00 - 21.00 – Conference Registration opens in the Hotel Foyer

Come along to register and pick up your information pack. Complete consent forms, etc. You will receive a warm welcome from our wonderful team of volunteers. Visit the information and fundraising stands. Meet old and new friends and have a coffee and a chat.

18.00 - 19.00 - Blair Athol - Opening Ceremony

THURSDAY – Willow Court Guest Accommodation Foyer

14.00-21.00 - A welcome desk will be in the foyer of the Willow Court Guest Accommodation, to assist you with directions. You will receive a warm welcome from our wonderful team of volunteers.

FRIDAY – STIRLING COURT HOTEL

09.00 -10.45 - Registration opens in the Hotel Foyer

Come along to register and pick up your information pack, complete consent forms, etc. You will receive a warm welcome from our wonderful team of volunteers.

10.15 -10.45 - Refreshments in Bar & Silver Glen

11.00 -11.15 - Welcome – Arlene Smyth

11.15 - 12.00 - Keynote Presentation - **“What have we learned in 25 years of TS CLINICS?”**
Prof Gerry Conway, Reproductive Endocrinologist and Ms Melanie Davies Fertility Specialist from London

12.00 -13.00 - Blair Athol- Cardiac Health in TS

Dr Claus Gravholt and Dr Helen Turner, personal stories & more TBC

Topics covered will be Blood Pressure, Heart Health, Current Guidelines, Information available, and Cardiac Alert Cards etc.

13.00 -14.00 - Lunch in Abbey Craig Restaurant and a chance to look at the information stands in the Silver Glen

14.00 -15.00 - Afternoon workshop 1

Topics covered will be Fertility, HRT, Growth, Puberty, and Speech Therapy

15.00 -15.30 - Refreshments

15.30 -16.30 - Afternoon workshop 2

Topics covered will be Education, Employment, Communication, Driving, friendships, Equality

16.30 -17.30 - Relaxed, getting to know you workshops, “Heart to Heart”. This is a chance to meet other ladies, parents, partners, Mum, Dads, Friends in small groups with the chance to listen and or share some of your story.

17.30 - Close of Friday sessions and workshops

17.30 - Onwards **See Social Programme**

Friday Kids Club

Children can be dropped off 15 minutes before the conference programme starts. Refreshments will be provided during the day.

If your child has personal property with them at Kids Club or TeenS Club you should label it clearly with their name. **The TSSS UK accepts no responsibility for personal property.**

Baby and Toddlers Programme

There will be free play, story and song time and creative play. It also helps to bring along a few of their own toys to play with.

Kids Club Programme

10 - 45 - On arrival, welcome and introductions

10.45 -13.00 - Morning Session - Name games and decoration of children's name badges, followed by arts and crafts then some games. Make a take home craft and crafts for the Saturday evening show followed by free play until lunch.

13.00 -13.45 - Lunch with parents. Please collect your child promptly as our volunteers also need lunch.

13.45 -17.30 - Afternoon session - Practice a simple routine to perform at the Saturday Evening Show with Sam & Daisy. Games, Free Play & complete crafts

17.30 -17.45 – Finish: Parents please pick up your children promptly

Friday TeenS Club

10.45 - Welcome and introductions with ice- breaker games.

Morning session - Games, singing and dance.

13.00 -13.45 - Lunch with parents if under 16 years. Please collect your child promptly as our volunteers also need lunch.

Afternoon sessions - Singing and dancing rehearsals

17 -30 - Finish: Parents please pick up your children promptly if under 16 years

This is where initial friendship bonds are made, and Teens are usually inseparable from here on!

Please welcome everyone with your usual warmth and kindness.

SATURDAY – STIRLING COURT HOTEL

09.00 - 11.00 – Fertility Options with TS Expert Panel - Ms Melanie Davies, and others TBC, Egg Freezing, Fertility Treatment, and Healthy Outcomes with Personal Stories on Surrogacy, Adoption and Egg Donation.

09.00 - 11.00 - Education issues faced in TS with TS Expert Panel - Prof David Skuse, Jeanne Wolstencroft, and others TBC
Speed Processing, Spatial Awareness, Poor Concentration and Memory, NVL, Solutions, Information Resources, etc.

09.00 - 11.00 - Individual workshops on Thyroid, Hearing, Foot care, Blood Pressure, Health & Well Being, Hearing, Diet, Stress etc.

11.00 - 11.30 - Refreshments

11.30 - 13.00 – Individual topic led workshops on Diabetes, Intimacy, and Friendships etc.

13.00 - 14.00 - Lunch in Abbey Craig restaurant and a chance to look at the information stands in the Silver Glen

14.00 - 15.00 - Pre-Natal Genetic Testing: with TS Expert Panel - Geneticist, Midwife, TBC
Information given with results, Decision Making, and Personal Stories

15.00 - 15.30 - Refreshments

15.30 - 16.30 – Individual topic led workshops
Feeding Issues, Food Intolerances, Coeliac, Speech Therapy, Anxiety, Well-being, etc.

15.30 - 16.30 - Relaxed, getting to know you workshops, “Heart to Heart” This is a chance to meet other Ladies, Parents, Partners, Mum, Dads, Friends in small groups with the chance to listen and or share some of your story.

16.30 - Close of Saturday sessions and workshops

Time to get ready for the amazing *“TSI 2020 Showtime “*

16.30 - Onwards **See Social Programme**

Saturday Kids Club

Children to be dropped off 15 minutes before the conference programme starts. Refreshments will be provided during the day.

Baby & Toddlers Programme

There will be free play, story and song time and creative play. It also helps to bring along a few of their own toys to play with.

Kids Club Programme

08.45 - Welcome back

Morning session - A surprise guest will visit, sing dance and read with you. Then some games, free play, until lunch.

13.00 - 13.45 - Lunch with parents. Please collect your child promptly as our volunteers also need lunch.

13.45 - 16.30 - Afternoon session - A final practice of their simple routine to perform at the Saturday Evening Show with Sam & Daisy. Games, Free Play & complete crafts

16.30- Finish: Parents please pick up your children promptly

Saturday TeenS Club

09.00 - Morning Session – We are delighted to welcome *Dale Vincent* to our conference. He is a Confidence Building Coach, International Speaker, Cognitive Behaviour and Timeline Therapists. We have designed a full programme to work through, covering Confidence Building, Games, Mindfulness, Confidential Q and A Sessions, and strategies to improve self-esteem and body image.

Dale is super cool, and I am sure you are all going to have a fabulous time with him.

13.00 - 13.45 - Lunch with parents. Please collect your child, if under 16 years of age, promptly as our volunteers also need lunch.

13.45 - 16.30 - Afternoon Sessions continue from the morning session with final singing and dancing rehearsals.

16.30 - Finish: Parents please pick up your children promptly if under 16 years of age.

Sunday morning

09.30 - 10.00 - A multi faith service

10.00 - 11.00 - TS Registries – Prof Faisal Ahmed – EuRRECa Project and others TBC
Working together on registries to improve our knowledge, information and research. What is available now and what might happen in the future.

10.00 - 11.00 - Relaxed, getting to know you workshops, “Heart to Heart”. This is a chance to meet other Ladies, Parents, Partners, Mum, Dads, Friends in small groups with the chance to listen and or share some of your story.

11.00 - 11.30 - Refreshments

11.30 - 13.00 - International Groups, sharing ideas, successes, fundraising tips etc.

13.00 - 14.00 - Lunch in Abbey Craig Restaurant.

14.00 - 15.00 - Relaxed, getting to know you workshops, “Heart to Heart” This is a chance to meet other Ladies, Parents, Partners, Mum, Dads, Friends in small groups with the chance to listen and or share some of your story.

14.00 - 15.00 - Active workshops, Dance, Self Defence, Walking, Swimming, Football

14.00 -15.00 - Craft workshops, Sewing, Art, Jewellery, Painting ceramics, Card making

14.00 -15.00- Mindfulness, Yoga, for adults. Family Connections for parents & children together, with Mindfulness, Yoga, Games with Occupational Therapy

15.00 -15.30 - Refreshments

15.30 -16.30 - TS International Board – Update on website, plans for the future suggestions from the delegates etc.

16.30 -17.00 - Closing ceremony and say our farewells

A choice of local tours will also be available to choose from.

Sunday Kids Club

Children to be dropped off 15 minutes before the conference programme starts. Refreshments will be provided during the day.

09.45 - It has been a busy few days for the children, today is more relaxed. We have a fun mini cinema to watch a family film, or free play for those who prefer not to watch the film.

Parents can take their children to join in Family Connection workshops or they can have a games and free play in the club.

13.00 - 13.45 Lunch with parents; please collect your child promptly as our volunteers need lunch too.

13.45 - 16.15 Followed by, a fun filled show by our children's entertainer.

16.30 - Children will join the closing ceremony, to sing the TS anthem and say our farewells

Sunday TeenS Club

10.00 -13.00 - Morning Session - Creative art session with Sam, where you will contribute to a lasting memory of TSI 2020

13.00 - 13.45 - Lunch with parents; if your child is under 16 years, please collect them promptly for lunch, as our volunteers need lunch too.

13.45 - 16.15 Creative art session with Sam, where you will contribute to a lasting memory of TSI 2020

16.30 -TeenS will join the closing ceremony to sing the TS anthem and say our farewells

Social programme during TSI 2020

Thursday Evening- Conversation, exercise or relaxation

Visit the Gym, have a swim, a walk, a drink with friends, dinner on or off campus, karaoke, music, glitter tattoos.

Friday Evening- Conversation, exercise or relaxation

Visit the Gym, have a swim, a walk, a drink with friends, dinner on or off campus, karaoke, rehearsals for the show, music, glitter tattoos.

Saturday Evening- It is party time, everyone gets dressed up & joins us in the Mac Roberts theatre for “TSI 2020 Showtime” The show will celebrate the talents of those who have TS, their families and friends. Together we will celebrate working, learning and sharing our knowledge.

“Together we are stronger “

The Gala Dinner will be held in the Abbey Craig Restaurant, followed by music, dancing and conversation.

(Don't forget to book your ticket as there is limited availability)

Sunday morning

A multi faith service

Afternoon & evening – A choice of various tours, excursions will be available.