



ASPECTS

Turner Syndrome Support Society Newsletter ©

Charity Reg No. 1080507

Volume 4: Issue 6: March 2010

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GIRLS JUST WANNA HAVE FUN!





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IMPORTANT DATES

TSSS 11 th Anniversary Conference.....	8 th to 10 th October 2010
BES Conference Manchester.....	15-18 th March 2010
Mother & Daughter Mini Cruise.....	26 th March 2010
TSSS Open Day in Nottingham area.....	19 th June 2010
TSSS Awareness Day.....	21 st June 2010
TSSS Open Day in Norwich area.....	10 th July 2010
BSPED Conference Manchester.....	3-5 th November 2010
TSSS Open Day in Oxford area (Provisional date).....	21 st November 2010

COVER STARS

The cover stars for this edition of *ASPECTS* are Sarah, Ella, Jodie and Sian !





EDITOR'S MESSAGE

by Joy



Hello everyone!

In my spiel in the last issue I promised to keep this short and I shall try and stick to that.

Welcome to my very first edition of *Aspec TS* as editor! I have to start by saying how honoured I am to be trusted with this position as I know how much you all enjoy and benefit from the newsletter. Simon and Sally have left me with huge boots to fill, having done a magnificent job over the last few years. Therefore, it's only right I start by thanking them for all their hard work. I only hope I can continue where they have left off and you continue to get as much out of it. As I keep saying I cannot do this without your input and, as much as those of you who know me will know I can talk for England, I'm sure you all have your own interesting stories and experiences to share so please do keep them coming in!

Hope you all had a great Christmas and New Year. Mine was a quiet one with my Mum in Norwich but very enjoyable nonetheless. Life isn't too bad for me at the minute - I am still temping for Sheffield City Council but am hoping to find myself on a more permanent footing job-wise in the fairly near future. I am still loving my little flat even if it is a pain having to clean, Hoover and dust myself!

I had my official graduation ceremony in November which was a very proud moment. I received my degree from Lord Robert Winston at Sheffield City Hall and my family were all there to witness it. Needless to say I did get a bit emotional by the end

of the day! I now can't wait to put my degree to good use and what better place to start than *Aspec TS*?

Anyway I did promise I would keep this short so I shall leave you to enjoy the rest of this newsletter. We have lots of exciting things coming up which you will read about and plenty of great ideas for fundraising so please join in and get involved in whatever way you can. To coin a phrase from a well known Supermarket... every little helps!

Take care everyone and hope to see you soon
Love Joy x

Chair's Message

by Hayley



Happy New Year to you all. I hope you all had a lovely Christmas and New Year, although it all seems a dim and distant memory now. Ours was lovely, if not a lot quieter than we had originally planned due to the bad weather.

I hope you all coped during the recent adverse weather. I didn't make it into work for three days during the bad weather and the rest of the time was a challenge getting in and out of work. Let's hope the bad weather is behind us and we can look forward to some warmer and longer days. This leads me very nicely onto the cruise. I am looking forward to our 3 day cruise very much indeed. It will be a wonderful opportunity for some R&R with some very good friends which after the cold, snowy, dark days





we're now putting behind us can't come soon enough for me.

I'm just back from the two day planning committee meeting in Derby. We had a very successful weekend and covered a lot and put our plans in place for this year. It is a bit quieter this year after the amazing 10th Anniversary year we had last year but still plenty going on so do read your *Aspec TS* carefully so that you don't miss anything.

Talking of *Aspec TS* can I just thank Simon and Sally for all their hard work over the last few years in putting this wonderful newsletter together and welcome Joy as the new editor. I know Joy will do a superb job in putting the newsletter together but she does need your stories and input to do so, so keep them coming in to her.

Back in November I attended the BSPED in Reading along with Arlene, Susie and Stephen. It was a very busy few days but well worth it to be able to raise awareness and improve knowledge amongst the medical profession. I also gave a presentation on the Thursday morning on "disclosure" from my personal view. This was very interesting and raised lots of issues and feedback. I was very nervous to start off as it was the first time I had used PowerPoint and given a presentation but the feedback I got was very positive. Disclosure is a huge issue and is something that we are looking to cover in our conference in October.

We will of course be attending the BES and BSPED medical conferences as in previous years. To fly the TSSS flag. These are both being held this year in Manchester and are ideal opportunities to talk to the medical profession, raise awareness and promote the 3 Tanners Appeal. The 3 Tanners is very relevant to them and the figures make very powerful reading and gets their attention.

I am planning to hold a quiz night at my Mum's pub in March to raise funds for the TSSS. This always seems a popular evening and we have a lot of fun, in aid of a fantastic cause. I'll be reporting back in future *Aspec TS* with pics.

On the home front, we are doing the Christmas run to Peterborough during the first weekend of February! We were unable to do this during Christmas/New Year because of the bad weather.

I'm looking forward to this very much as we've not seen them since October at Isaac's christening.

I look forward to seeing as many of you as possible at the various events coming up during the next 12 months and catching up with all that's going on.

Take care

Hayley xx

Arlene's Report

Happy New Year to you all, I hope you had a super Christmas and have a prosperous 2010. After such a busy year last year I am hoping that this year will be at a slightly slower pace. We shall just have to wait and see. We had to postpone our planning meeting because of the bad weather, so we have just had a very good planning meeting where we have set dates for the forthcoming year so please make a note of all the relevant dates in your diary. We very much appreciated all our trustees & committee members taking the time needed to travel and attend the meetings. We would not be able to do as much as we do if they were not as dedicated, thank you all very much. Hayley has her chairing skills down to a tee now and does an excellent job.

My apologies to anyone who was trying to get in touch during the first two weeks of January between ice, frozen pipes and having no water I was working from home and the office and it was not ideal. I am sorry if I missed your call please do get back to me if I have not responded to you yet. I do have a bit of a back log to get through.

This newsletter is Joy's first as our new editor I would like to welcome Joy back on to the committee. I am sure she will do an excellent job as *Aspec TS* editor. Please support her by sending in articles to be published. Our appreciation and thanks to Simon & Sally for all their hard work over the years with the newsletter we have seen it transform over the years. To produce such a bumper edition as the December newsletter lets you go out on a high. Our thanks to Merck Serono for giving the TSSS a grant to allow us to produce our first fully colour newsletter.

After a lot of discussion we have decided to return to the Parkhall Hotel in Chorley near Preston for our





11th Annual Conference on the 8 - 10th of October 2010 a booking form will be in the June newsletter and on the website ASAP. We will do our best to negotiate a good price and we have been working on a whole new childrens programme for the kids to enjoy. All comments on the exit questionnaires have been considered and we are working hard to deal with the few teething problems we did have. We look forward to seeing many of you at conference in October.

I am delighted to tell you that the final draft of the new Jeans 4 Genes leaflet is available from www.tss.org.uk or in hard copy from the TSSS office. Thank you to those of you who made comments on the leaflet following the conference. Many thanks to J4G for the funding and their patience as we have ran over our deadline due to a number of unforeseen circumstances. To Dr Paul Chadwick and all of you who took part your help is very much appreciated. At last we will have a leaflet for women who have TS to help them think positively about themselves.

Following the NICE Growth Hormone Appraisal meeting I am pleased to say that Growth Hormone treatment continues to be available to those girls who have TS. You can see the full guidance on the NICE website www.nice.org look for Growth Hormone Technology Appraisal.

I was invited to join the committee of The Scottish Endocrine Managed Clinical Network by Prof Chris Kelner in November. I was pleased to accept and have so far attended two meetings which have been interesting. As the network continues to develop I will keep you up to date with information relevant to patients. There will be a website set up and we will link to the site via our site.

Our thanks to the Society of Endocrinology who kindly gave us an extension to our deadline for our grant report on the production of our new fact sheet series. Which I am pleased to say are now on the TSSS website and also available in hard copy from the TSSS office. Do have a look and let us know what you think about them. We do hope they will prove helpful to you.

I attended the Novo Nordisk Nurses meeting in January which was very interesting and it gave me the chance to meet some nurses and give them some TSSS information for their patients.

In February I will attend the Merck Serono Nurses meeting again a great opportunity to meet some nurses and give them some TSSS information.

Our thanks to our benefactor companies Ferring, Ipsen, and Novo Nordisk & Pfizer who help us to deliver services to our members, their help ensure we continue to offer support and information to members throughout the country. We very much appreciate their support through unrestricted educational grants.

Best wishes Arlene

Fundraising

Our sincere thanks go to everyone who raises money for the TSSS in this difficult economic climate. The following have raised money for us in the recent months. Thanks to you all.



Ann Evans donated £40 to the Society.

The Beckman Family donated £50 to the Society.

Elizabeth White donated £50 to the Society.

The Rebecca Varley Dance Academy raised £200 at their Christmas Ball.

Redhill Preparatory School & Montessori Nursery raised £351.09 at their Christmas Nativity Play and donated it all to the Society.

James Spencer has donated another £100 to the Society.

Carers of Nina Soiza donated £70 to the Society.

A £250 donation from **Andrew McMurtrie's place**

Smith & Williamson Investment Management.

Melanie & John Russell donated £100 to the Society.

Joy Taylor donated £10 to the Society.

Pat Rogers donated £10 to the Society.

Mrs M Parker donated £20 to the Society.

The Rotary Club of Colwall donated £250 to the Society after Arlene went and talked to the members.





The **Coventry Rangers Football Club** raised £370 by running in the Coventry Fun Run in June 09.
Carolyn Brewer held a pamper day at her local beauticians and they raised £100 for the Society.
A member took part in a market research survey and the company made a £10 donation to the Society.
Barbara Drew raised £450 for the Society by running in the Dublin 10k last year.



3 Tanners Appeal Update

Initially the 3 Tanners Appeal was due to run for the year of our 10th anniversary, however, due to the fantastic response we have had from all of our members and the medical professionals we have decided that the Appeal will be ongoing.

Week on week we hear of girls being diagnosed well into their teens and some even later. Early diagnosis is vital so that girls receive the correct management of TS and have the support they need helping them to lead happy and fulfilled lives.

There is no doubt it is a large mountain to climb in terms of raising awareness of Turner Syndrome and improving diagnosis, but bit by bit progress is being made. And of course it has a financial impact. Last year fundraising was amazing raising over £28,000 this year we are aiming for £30k.

It is a significant target we know, but due to the economic climate there is less funding available to the TSSS, and therefore fundraising in general is more important than ever as are our membership fees. It helps us keep doing what we do. We have already planned which medical conferences we are attending this year, having chosen those which will have the maximum impact for the least spend.

So thank you for your fundraising, you are as always amazing.. Jane x

Fundraising made easy.....



I would like to help fundraise but I am so busy I don't have the time.....

We may have some solutions to how you can do so much, for so little time

Thank you for your continued support. It is greatly appreciated





www.easyfundraising.org.uk



When you shop online, go on to this site before you shop and follow the links to your normal stores. Please select the Turner Syndrome Support Society as your chosen charity. There are over 2000 stores on here, so well worth a look

Booking your summer holiday ?



Please check out the deals on www.travel2give.org.uk as booking your holiday through them will raise funds. Wishing you a great time !

Unwanted and Unloved Mobile Phones



Collect 30, and we can arrange free collection, alternatively hand them in at a TSSS event, we earn £2.50 for each mobile so please check out those drawers

Great Weather Lottery



Why not join the great weather lottery, That way you have a chance of winning too..... Good Luck
www.theweatherlottery.com

Awareness Day Raffle or Casual Day

Would your work let you run a raffle on the week of 21st June, or perhaps a casual day at work or school

Rotary

Why not contact your local Rotary or Lions club, and see if they would be able to help with fundraising.

50/50 Club

The 50/50 Club Membership at January 2010 is 105.

Please find below the 50/50 numbers for January and February 2010:

January 2010

- 1st Place - Number 97 - Jill Widdowson - £26.25
- 2nd Place - Number 87 - Mr V Soiza - £15.78
- 3rd Place - Number 63 - Frances Hunt - £10.47

February 2010

- 1st Place - Number 87 - Mr V Soiza - £26.25
- 2nd Place - Number 6 - Annette Clark - £15.78
- 3rd Place - Number 5 - Luke Walker - £10.47

If you know of anyone who would like to join the 50/50 Club then please contact Arlene at Head Office to obtain an application form and Standing Order mandate.

Many thanks for your continued support.

Tracey and Jane





REACH FOR THE STARS

Over the summer months we worked on a competition called "Reach for the Stars" with Novo Nordisk Ltd to produce a book with some stories from children who took Growth Hormone injections for a variety of reasons. This was a project to benefit the TSSS, The Child Growth Foundation & the Pituitary Foundation. We are delighted with the finished book and very pleased that three of our members are featured in the book. Congratulations! **To Laura, Cherry & Lauren-** we are very proud of you and love your stories. Sharing your hopes and dreams will help other children who take Growth Hormone injections too. The books are available to buy from our website for a donation of £5.99 with all proceeds from the sales going to the TSSS.

Questionnaire - An investigation into the perceptions of those with Turner Syndrome and their families

Enclosed in this newsletter is an information sheet and questionnaire entitled "An investigation into the perceptions of those with Turner Syndrome and their families." Please take the time to read these. If you are happy to, please complete and return the questionnaire in the enclosed FREEPOST envelope by 1st May 2010. Make sure you read all the questions carefully and don't forget the back page!

Jessica Hensman is a Genetic counselling student working in Cardiff; the TSSS are pleased to be working in collaboration with her on this study. The TSSS values and respects the privacy of all its members and never discloses personal data information to a third party. Hence the questionnaire being sent out with the newsletter. We are pleased that individual TSSS members are being given the opportunity to share their thoughts, views and experiences with Geneticists and other interested parties. We know from experience how powerful personal experiences can be.

Jessica will provide us with an update on her findings in due course. If you have any questions you can contact me Arlene at Turner.Syndrome@tss.org.uk or Jessica Hensman using the contact details on the enclosed information sheet.

TSSS Fact Sheets Series

Our thanks to the Society of Endocrinology who kindly gave us an extension to our deadline for our grant report on the production of our new fact sheet series. Which I am pleased to say are now on the TSSS website www.tss.org.uk and also available in hard copy from the TSSS office. Do have a look and let us know what you think about them. We do hope they will prove helpful to you.

Diagnosing TS Booklets

This excellent booklet has been sponsored by Ipsen to help improve diagnosis of TS and goes hand in hand with our "The Three Tanners Appeal" copies are available from the office to be given to your GP or Paediatrician. We really appreciate being able to have such a booklets to help doctors with the difficult tasks of diagnosing TS. We are very grateful to Ipsen for their support.

We also have little cards to encourage diagnosis which you can also pass to your health professionals. Don't forget the Health Checks Lists are still available from the office too.

Members Contact List 2010

A list of members for 08/09 is currently available from the office on request. It is a list of members who have kindly agreed to be contacts for other members. The current list needs to be updated this year, so if you want to be on the next one please e-mail me on Turner.Syndrome@tss.org.uk with your name, area, mobile or landline number plus your e-mail and we will get the list updated. If you are not on e-mail, post or fax the information to me at the office.

TSSS OPEN DAYS
Nottingham

Remember to request a booking form from the TSSS Office or download from the website the Open Day will be on Sat 19th June 2010 all bookings must be received by 1st of June.





Norwich

Remember to request a booking form from the TSSS Office or download from the website the Open Day will be on Sat 10th July 2010 all bookings must be received by 20th June.

To Order and view the pictures taken at conference you can do so by going on to the website address below.

<http://3256.e-printphoto.co.uk/keithingley>

TSSS Website

We are currently redesigning the TSSS website to bring it up to date and to keep it current. We are adding a photo gallery, downloadable fact sheets will be added as and when they become available, plus lost more. Please keep checking to see what's new on www.tss.org.uk please let us know what you think?

Rare Disease Awareness Days 28th February 2010

There are receptions being held in Scotland, Wales and Ireland this year in association with the Genetic Interest Group [GIG] of which the TSSS are members. The TSSS hopes to have representatives at each event to raise awareness of Turner Syndrome. Have a look on their website www.rarediseaseday.org.uk for further information.

Mother and Daughter Cruise 2010

There are 49 of us setting sail on the 26th of March for a fun cruise to Bilbao in Spain. Travel 2 Give has done a great job with the booking and I look forward to seeing everyone in Portsmouth. You will see plenty of photos in the June newsletter.



MEMBERSHIP REMINDER

Membership is due on the 1st of June every year, with a 3 months grace period either side of June for new members. Membership costs £25 per year if you pay by cheque or £20 per year or £2 per month by standing order what ever suits you best. It is a great help to the TSSS if you pay by standing order as it means we do not need to remind you, it just happens every month or year. Remember you have control of a standing order not us. If you have any queries please do not hesitate to contact the TSSS office.

Mrs TSSS reports



Hello Everyone,

Welcome to our 1st issue of *Aspec TS* for 2010. I cannot believe that it is nearly March already. We have had a busy few months at home what with Geoffrey's, mine and Melissa's birthdays. It costs Steve a fortune but of course I am worth it.

So how did everyone cope with the few snow days we had in England. Everything came to a standstill in Oxfordshire and all public transport stopped so I





had to take 2 days off work (what a shame). Geoffrey's school was closed for 4 days which he loved, Steve had to work from home and Melissa of course went to work every day as she only has to walk 10 mins to get there so she was not impressed at all. In fact it took me 3 hours to get into work one day and I only live 6 miles away although I must admit it was fun struggling to work and arriving there at 11am (I must have been mad even to attempt it).

We have just had our 1st Committee Meeting for 2010 which was held in Derby 30/31st Jan. It was a very busy weekend and we managed to achieve everything that was on our Agenda. We have organised what/when/where everything for 2010 which is no easy matter trying to fit everything in and making sure that Committee/Trustee Members can attend all these meetings. We are of course going to the BES and BPSD this year. These are both being held in Manchester this year which Arlene will attend. On both occasions Arlene has Committee/Trustee Members helping her out as that is a busy time during these conferences for Arlene and she does require extra bodies so thank you to those that have volunteered to help Arlene.

The weekend was eventful enough without most of us either having a Bronchial Chest Infection, Colds, Coughs, Tummy Upsets so lots of germs floating about. Arlene was full of beans as usual and was amazed that she never had any bugs. A week later guess what, yes Arlene has caught the bug now so it has spread itself around all of us. I am still on antibiotics, had a chest x-ray last week and waiting for my results so fingers crossed that it comes back clear which I am sure it will.

I hope all you women/girls are getting organised for next Mother/Daughter weekend which is 26/29th March. We are all off on a mini cruise to Bilbao in Spain. Also for the first time Melissa and I are coming along too with a very good friend of mine Alison and her daughter Jessie who is 15. Some of you may remember them as they came along to a meeting in Birmingham a few years ago. Jessie does not have TS but was diagnosed with a brain tumour which has resulted in her being on many many drugs including growth hormone. Anyway Jessie is very excited about this holiday and is looking forward to making new friends. I am sure that all the girls will make her more than welcome.

I will finish up now as I must get this off to our NEW EDITOR Joy (sorry Joy I know this is late). I know that this is your first newsletter and you are under pressure but we all know that you will do a fantastic job and I must thank Simon and Sally for all their hard work in producing *Aspec 75* for as long as they did. So Joy as Captain Mainwaring would say "Don't Panic". Arlene, Simon and the Committee are here to help and guide you and please do not hesitate to "Tell us off" if we are late with our publications as I know how we Turner Women work and we always like to be organised at all times which to me is not a bad thing !!!!!!! Good luck in your first issue and enjoy it for the next 20 YEARS , thanks Joy !!!!!

Mrs TSSS x

***Editor's note-** Thank you Susie for those kind words!

Pat writes



Hello everyone!

I am really looking forward to our mini-cruise over to Bilbao. It will be good to see everyone and I'm really looking forward to seeing the Guggenheim too, and hopefully catching sight of a few whales along the way. It's a long way down for me so I'll be staying over in Portsmouth on the Monday night and sneaking a bit of time to see an exhibition in London on the way back. I'm really pleased that it is open to female friends of mothers and daughters as well as the mums and daughters.

Hayley and I have been having a few thoughts about more social events for us older women (ie anyone





who is not a young twenty something and feels like coming along) so if you have any ideas let us know. We want it to be friendly and informal and be simply a chance to enjoy something together as a group of friends, whether it's a show, a gallery or anything else that we might choose to do.

You may well see details of things that are happening if you keep an eye on our new facebook group. "TSSS Turner Syndrome Support Society UK." It's in its early stages but members are already signing up and of course you are all welcome there. We are hoping that it will build into a good publicity and networking tool for us all and be a place where you can find out about what's going on in between reading your copy of *Aspec TS*. It will help us all keep in touch, and given that we are all so spread out that's a really good thing.

My partner Nick and I will be having an extra journey down to the south coast in early March, before the cruise, to pick up our new puppy Freya. She is adorable, as some of you will know from my facebook page, but then puppies don't have to work very hard to be adorable! I am very excited and by the time that you are reading this she will have arrived and no doubt she will be making her presence felt. I just hope that Fern isn't too horrified when there is another Field Spaniel competing for scraps of bacon and hugs. I shall submit a photo of her for the next *Aspec TS* as soon as she is safely here so that you can all go Aahhhhhh! It might not be anything to do with Turner Syndrome but hey.....

Take Care and hope to see or speak to you soon.

Pat x

Teens Report

Hi girls, Hope you all had a lovely winter and the bad weather didn't affect you too badly. The snow was an inconvenience, but at least we got a bit of time off school thanks to it!

As you may know, this year at Conference we're going to be doing songs from a few different musicals, so if you have any ideas or preferences for songs or musicals, please let us know. We'd love everyone to get involved, so even if you're not a teen

and you want to perform a song, again please let us know.

This March we have a very exciting Mother-Daughter outing. For some reason they're letting us on a cruise ship together. For those who are going on the cruise, Jenna looks forward to seeing you there (Ellie unfortunately can't make it). We understand that not everyone will be able to go on the cruise so we look forward to seeing many of you at various open days and events.

I'd like to leave you with a quote:

"Take pride in how far you have come, and have faith in how far you can go".

Jenna and Ellie x x x



Young Adults Update

FROM KYLIE AND CHARLOTTE

Hi all,

We hope you are all well & had a wonderful Christmas and New Year. We have just finished the annual planning committee meeting to plan how the TSSS will grow & develop over the next year. We also hope that those of you going on the Mother & Daughter cruise have a lovely time. There are also Open Days planned for throughout the year, so we hope to see you soon.

KYLIE SAYS

I have been busy working away & enjoying being a nanny & looking after 2 lovely little girls. Unfortunately, my lovely wee dog Mac took very ill & had to be put to sleep at New Year so this has been





very hard but we know he is at peace now & I'm in negotiation with my Mum about a new puppy so watch this space! Take care all & I hope to see you soon.

CHARLOTTE SAYS

I have been busy working for agencies doing supply teaching assistant work, which I am really enjoying as I am learning new skills and getting experience of working with different age groups of children. We have lots of fun events coming up this year, so hope to see you all soon! Take care xxx



My TS Life- Elizabeth's Story

***editors note- this is a new feature I am hoping to introduce to *Aspec TS*. It is a chance for anyone and everyone to write in and share their stories of life with TS. You don't have to be a girl or woman with TS- parents, siblings, families, friends, pets- anyone is welcome to write in about what TS means to them. To start us off this issue we have an inspiring story from a young lady with TS called Elizabeth...**

My name is Elizabeth. I am 24 years old from Sutton Coldfield, West Midlands. I was diagnosed with Turner Syndrome when I was 2 years old. My parents were very open about my condition right from the start and always answered any questions I had honestly. My parents went to a Turner Syndrome conference in Toronto, Canada in order to

meet other parents and to learn more about the condition and available treatment options. Health wise, I have been lucky so far as I don't suffer with any of the heart or kidney conditions; however I do have hearing problems and I suffer with persistent calcium lumps and keloid scarring. I also have auto-immune conditions such as an under active thyroid, occasional Alopecia (hair loss) and Coeliac disease. I was diagnosed with Coeliac Disease a year ago in September 2008. Since I was diagnosed with Turner Syndrome I have had 14 operations. These include grommets, T-tubes, tonsil and adenoid removal; squint repair, lumpectomies, teeth removal for orthodontic work and my two most recent operations were to insert Bone Anchored Hearing Aids. This involved my consultant, Mr David Proops, inserting a titanium pin into the conductive bone in my skull. Three months post surgery; I had my hearing aids fitted. Since I've had this done, I have not had any ear infections.

Despite my medical problems, I have never felt it would stop my doing whatever I wanted to. Whatever the doctors have said I wouldn't/ couldn't do, I have proved the doctors wrong. For example the doctors said that due to my hearing impairment I would not be able to play a musical instrument. I can now play the flute and clarinet and was part of the school orchestras. Another example is my height. When I was first diagnosed with Turner Syndrome, my doctors did not think I would reach 5ft in height. I am now 5ft 2 inches and I am now taller than my older sister, who has no medical condition, by an inch. We now have our own nicknames. I'm Big Little Sis and she is Little Big Sis. I also passed my driving test on my second attempt at the age of 17. I love the independence.

In regards to school work, I did well in my GCSEs passing all 9 with A-C grades and got all 3 A-Levels. After I did my A-Levels I went to University of Derby and I graduated with a 2.1 honours degree in Early Childhood Studies. I am currently completing my two year postgraduate diploma in Paediatric nursing. Even though I have not decided what aspect of paediatric nursing I want to specialise in, I think, once I qualify in April 2010, I would like to work in a field in which I can help other children and parents with similar problems that I have suffered with. The reason for this is because I have seen firsthand how upsetting it is for the child, parents and family to be told their child has a medical condition, therefore I feel I would like to help them through these times.





I have recently moved out of my parent's home into my own house close to a train station, which is handy for me to get to and from my nurse placements and work.

Even though my condition can get me down sometimes, especially my hearing, I do not see myself as any different to anyone else. My achievements highlight this. If you would like to contact me for support then feel free. Remember we are no different to anyone else!

***Editor's note-** Thank you Elizabeth for sharing your inspirational story with us. If anyone would like to contact Elizabeth then please contact us via the TSSS office.

If Elizabeth's story has inspired you to share your experiences of life with TS please get in touch....

THANK YOU FROM SIAN

I would like to say thanks for all the cards and messages everyone sent for my 18th birthday. I had a great weekend celebrating! Ella, Sarah and Jodie managed to make it to my party despite the snow and we had a brilliant time especially on the karaoke. Can't wait to see everyone again at the Conference this year!

Love Sian xxxx



GET WELL SOON SASHA!

We were sorry to hear that one of our members, Sasha Wilks, has been poorly. We hope you get well soon Sasha and are sending lots of love! From all the girls and all your friends at the TSSS x

A Book Review by Pat

A Cracking of the Heart. David Horowitz.

This is an account, by the writer David Horowitz, of the life of his daughter Sarah, a writer and political activist, which was written after her early death at the age of 44 from heart complications associated with her Turner Syndrome.

It is a very moving and heartfelt book, fiercely honest in the way that only someone writing their way through deep sadness can be, a compassionate record of his relationship with his daughter, which shines a light into the dark places of his grief and tries to make sense of their joys and difficulties together as he slowly gets to know her in a new way by reading her writing and finding out more about the parts of her life which they didn't share.

Sarah was clever and creative, a caring woman with a strong social conscience, loved by her friends but shy of developing relationships with the opposite sex. Thanks to her Turner syndrome she was physically short and far from strong, with a weak heart and hips and poor hearing, but she never let this hold her back and led a full and active life, politically engaged and always ready to champion the cause of anyone who needed help.

As I read David Horowitz's book I was moved by his openness, his willingness to go to difficult places in order to understand his lost daughter better and I came to like him very much. He is hard on himself, perhaps harder than he needs to be, but grief leads you to think that way sometimes and understanding leads to acceptance. This is the process which he describes in the book.

I was able to read with an understanding and insight based on personal experience which many of you reading this will share in your own way. If there had been a false note I would have known, and not through cleverness but through personal identification and spending time during the last ten years listening to the experiences of others who faced similar challenges to those that Sarah faced.





I know that David Horowitz is writing with truth and clarity because I have met women like Sarah and I have met parents who felt as he did when he is describing their relationship. I am confident that many of you, whatever your association with Turner Syndrome stems from will find many things which you identify with and plenty to challenge you and make you think.

This is a brave and honest book and I wish that I could thank him personally for writing it. Sadly I will never meet Sarah but I feel that I know her through his account and through the people that I have met. She would be very proud of her father.

Pat Rogers.

Don't Stop Me Now Project

As a parent, at the time of your daughter's diagnosis, let's face it, is generally a tough time. Not only have you got to take everything in and accept it, you outwardly have to be constantly positive. You get overloaded with heavy reading material, you feel that life as you knew it has disappeared and all in all it is a very difficult time.

The age of your daughter's diagnosis can make a difference to how you feel, and how you begin to look forward. It is easy to forget the positives amidst all the literature.

It started when I looked back to our daughter's diagnosis aged 9, and how that impacted on the whole family, yes we have had many challenges, yes we have had to look at teaching some things in a different way, yes we have sometimes had to teach the obvious, yes she is very determined, yes she is beautiful, yes she graduated from Leeds University last year, yes she is a caring and considerate person, yes we are well proud of her, and this has now led to the TSSS Don't Stop Me Now project

Don't Stop Me Now - what is it?

We need your help please, we want to show, that however it may feel in the beginning, that having Turner Syndrome doesn't stop you doing whatever you want to do.

We are creating a photo document, showing photos of girls and women with TS doing everyday hobbies, activities and at work. It will be something that newly diagnosed girls and women and parents of girls can look at, amidst all the heavy reading. They will see that the vast majority of girls and women with TS lead happy and fulfilled lives.

As it will be a document download on the TSSS website, if you send me any photos you are agreeing for them to be used by the TSSS, it is important that if there are other people in the photograph that you have their permission to use the photo.

So what photos do we need?

Hobbies, Activities, and at work, here are a few ideas.

Brownies, Guides, Gymnastics, Cycling, Judo, Singing, Playing Musical instruments, Acting, Skiing, Horse Riding, Running, Camping, Duke of Edinburgh, Drama, Rock climbing, Celebrations, Weddings, Graduations, Families, and at work.... Anything at all.....

Please don't be offended if we don't use your photo in Version 1, this project will run and run, so there will be other downloads available at later dates, we may even put it on a disk, if we can find a sponsor.....



Where should I send the photo?

If you are on facebook, then send a request to join the group which is called Don't Stop Me Now project, you can then add the photos on.

Or email them to jane@tsssuk.org.uk

By Jane Raper.





A Problem Shared....

***Editor's note:** When I first agreed to take over *Aspec TS* I thought about what it was that I benefited most from being part of the Society and undoubtedly it was being able to share my concerns and worries with other girls and women with TS. I know how much the parents and friends benefit from sharing their worries and concerns too so I thought one of the new features I would introduce to *Aspects* would be "A Problem Shared..." where anyone can write in with a problem or concern relating to life with TS and other members will have chance to reply in the following issue with their solutions and tips. You do not have to be a girl or women with TS to write in- parents and friends can also feel free to write in with any issues they are worried about and if they wish they can remain completely anonymous. To start us off Jess has written in with an issue about driving....

Hi, I have been learning to drive now for around 3 years and I started driving in an automatic car straight away because I thought that would be the best option for me. However, I am still struggling with spatial awareness, as I still seem to get close to cars and also I find it hard to reverse. I wondered if anyone had any tips or advice on these problems or driving in general as I am coming up to my sixth test now and would love to pass...



So if anyone has any helpful hints for Jess or would like to share how they coped in a similar situation please get writing or e-mailing in. This feature cannot work without your input so however silly you think your reply might be your hints and tips could well help Jess and others learning to drive like her...

Write to the TSSS office or e-mail joy@tsss.org.uk - please include "A Problem Shared..." in the subject heading of your e-mails.

What A Difference A Year Makes- My Journey By Carolyn

Let's start at the very beginning, that's a very good place to start Well, maybe I should start a year ago although it really started when I was born in 1955 - I'll let you work that one out!!!!

I was diagnosed with TS at the age of 20 in 1974, and have been attending the London clinic for about the last 6 years, receiving all the checks - thank goodness. Well, a year ago, I suffered an acute attack of vertigo, and that is when this particular part of my journey began.

At first it was thought I had labrynthisytyus, an inner ear infection, but it did not clear as expected and I was sent for balance and hearing tests. The results had the team I was under a little baffled and I was sent for an MRI scan - scary. This was duly carried out and a follow-up appointment arranged. But, low and behold, I received a call to go in to see a consultant - pronto. This is when I was informed I had an adenoma of the Pituitary gland which would need removing. So, what next

Luckily the consultant I saw in ENT had read my notes and realised that I was under Gerry Conway already, so referred me back to him and an urgent appointment was made. I was referred to a neurosurgeon and ophthalmologist linked to UCLH as my peripheral vision had been affected. Following appointments and checks, which included a routine MRI of my heart, and a thorough eye check, I was admitted to hospital and the adenoma, which turned out to be an oncocytoma, was removed. Here I would like to add a word of thanks to everyone involved in my treatment and care. I couldn't have been looked





after better - all concerned were kind, understanding and reassuring.

I am now having follow-up checks and appropriate medication is being sorted. It all happened so suddenly I am just grateful that I am as well as I am now and that I was 'in the loop' already

It was great seeing everyone at the conference - it was like being let out of a cage and flying free. What a wonderful evening Saturday was and a great celebration of 10 years of the Society. Thank you Arlene and the team for all the hard work you put into it. And thank you to Carly for showing me her growth hormone pen, she made me feel better about having to go onto growth hormone myself. Would be nice if it means a gain a few inches - though I don't really think there is any chance of that !!!!!

Go for all the checks you can girls, they really are beneficial, and any support you can give to help obtain free prescriptions for the medication required to improve our quality of life I feel is essential, as it helps us function at an optimum level. The costs incurred could well be much less than having to have more costly treatment if a condition had deteriorated and needed surgery for example. *PREVENTION IS BETTER THAN CURE.*

Thank you for all your support, and for the basket of fruit. It seemed a shame to disturb it, it looked so nice, but I can assure you it didn't stay intact very long.

Take care and look after yourselves.

Carolyn
Carolyn7c@yahoo.co.uk

Good News and Thank you! By Brigitte

Some of you may be aware from having read in *Aspec 75*, or heard at the Conference in October 2007, about the fact that I have frozen my eggs for

our daughter to use in the future, if she should wish to, and the attempts we were making to change the law to allow the eggs to be frozen for more than the ten years currently permitted. We felt that it was important for all prematurely infertile children to have some hope and choice so we persevered to try and make the necessary changes in the law.

I took it to our local MP who in turn took it to Parliament on our behalf. Throughout the whole process I talked/discussed the matter with many individuals and organizations. I appeared on Woman's Hour, Radio 5 Live: The Victoria Derbyshire Show, ITV's This Morning and in many newspapers both local and national. Our local paper, The Manchester Evening News ran an Editorial Comment on Tuesday 27th May 2008 supporting the call for reform. I changed our names and was photographed for the papers in silhouette and on This Morning they filmed the back of my head so that we were not personally identified. This was only because we were not highlighting either me or my daughter, simply the issue itself for us and all other families similarly affected.

It seems that we tried at the right time as the Human Fertilisation & Embryology Act was being revised in 2008 so it was possible to request an amendment. Whilst it did not form part of the Act itself, it was agreed by the Department of Health that it was an area which needed looking into and was being considered as one of the Statutory Instruments to support the revised Act. I asked in *Aspec 75* this March for your help in responding by e mail to the Consultation Document which they produced. We needed many voices to support for the changes. Many of you did respond and it seems they listened.

Statutory Instrument 2009 No 1582 - Human Fertilisation and Embryology (Statutory Storage Period for Embryos and Gametes) Regulations 2009 came into force on 1 October 2009.

It gives the opportunity to extend the storage period beyond 10 years subject to the donor's written consent and a medical practitioner confirming that the recipient is prematurely infertile. The extension can be requested every ten years subject to a maximum of 55 years.

This is brilliant news as it means that my frozen eggs can be kept until, and if, our daughter wishes to





use them. She will never be obligated, she now has choice and some hope which was all we set out to achieve. The new regulation will also benefit any individual who is prematurely infertile as a result of any other medical condition, not only Turner Syndrome, so will give hope to many individuals.

Just as we were beginning to absorb the changes (and the clinic had started to prepare the necessary paperwork for the future) we learnt that the House of Lords were to put forward a fatal motion to annul the regulations.

This basically means that whilst the regulations were passed the House of Lords have the right to overturn any new laws. We did not know that this was a possibility and to say we were disappointed was an understatement.

Arlene (despite having a million and one things to do plus fighting off the flu) put a briefing document together to support the new regulations on behalf of the TSSS and I prepared one from the point of view of a parent. These were sent into the Department of Health and to various members of the House of Lords. We wanted our views to be considered during the debate which was to take place the next day.

I then watched the debate live, on the computer live feed, which was quite a surreal experience and was very nerve wracking. It started at 7.30pm and finished at 8.55pm one Wednesday in October. Earl Howe voiced his concerns and ten Lords and Baronesses then took part in the debate including Lord Winston. The Minister for Health answered their concerns but I still had no idea what the outcome would be (if they decided to vote and voted against we would have to start the whole process again). Earl Howe spoke again and finished with saying "I withdraw the motion". Not even a need for a vote.

That was it - we had won - the new Regulations could stand. It is now the Law and I am told by Andrew Stunell (our MP who took it forward for us in the first place) that it can now not be touched.

If you would like to read it in more detail http://www.opsi.gov.uk/si/si2009/uksi_20091582_en_1 is the link to the new Statutory Instrument and <http://www.parliament.the-stationery-office.co.uk/pa/ld200809/ldhansrd/text/91021-0010.htm> is the link to the full debate on Hansard.

So a massive Thank You to all of you who have listened and supported over the years and especially to those of you who took the trouble to send an e mail to support the changes. Without all of your help we would not have made this difference for our girls.

It will never to a perfect solution, there is no guarantee of success and I know that it is not for all, but hope and choice is important.

As a Society, in this 10th Anniversary Year, we have made a big difference. We have changed the Law. A big success and achievement for the youngest but biggest Turner Syndrome Society in the world.

Brigitte

Fundraising Pamper Evening



Just before Christmas Vicky and Amy at Revive Beauty and Tanning in Harefield put together a fundraising package to help raise funds and awareness for Turner Syndrome and the TSSS - and wow, were we pampered and looked after. As well as some fantastic treatments there were gift packs (ideal Christmas presents), mince pies and champagne on offer. Also TSSS pens, keyrings, coasters etc. were available. Their regular clients joined in and asked about TS, and the local shopkeepers put their hands in their pockets too. Everyone who attended can also look forward using a voucher for treatment in January - good way to chase away the post Christmas blues and get ready for spring.





Altogether we managed to raise £100.00 as well as raised awareness, so, A GREAT BIG THANK YOU to Vicky and Amy for all their hard work and support, and to all my good friends who came along. We all enjoyed a fantastic day.

You can learn more about Revive and see some photo's of the event on their website - info@revivesalon.co.uk

Thought for the quarter

**Nothing is too hard to do
If your faith is strong and true
So 'Never give up' and never stop
Just Journey on to the Mountaintop!**

Cheers

Carolyn Brewer

Thank You!



A big thank you to Mark Kotiw and the Coventry Rangers Football Team who chose the TSSS as their nominated charity when they ran the Coventry Fun Run back in June. They raised £370 for the TSSS so thank you very much from all of us!

A Turner Syndrome Project in South Wales

My name is Esther Godfrey and I am a final year medical student training at Cardiff University. I have recently completed a study of children's services in South Wales, looking at how children and adolescents with Turner Syndrome reach a diagnosis and their initial management.

During my project, I had the opportunity to talk to two girls with Turner Syndrome and their mums

about their experiences, which was invaluable and gave me an insight into how different girls can have such different experiences of Turner Syndrome. On talking to these girls, it also became clear that a timely diagnosis can be invaluable, helping families cope with any educational difficulties and associated medical problems from a young age.

One of the most important things that I have learnt during this project is that many girls with Turner Syndrome do not demonstrate the characteristic features of this disorder and can remain undiagnosed for many years, despite having had contact with medical services. I will be presenting my Turner Syndrome project at the Welsh Paediatric Society Conference in Cardiff next autumn. During my presentation, I would like to highlight to the doctors who attend the conference that medical practitioners have to think again about what many girls with Turner Syndrome look like. In medical literature, girls with Turner Syndrome have all of the characteristic features and I have learnt that in reality, this just isn't the case. Only a minority of girls with Turner Syndrome demonstrate the characteristic features and I hope that I continue to remember this throughout my career as a doctor, so that I can do my best to make a diagnosis of Turner Syndrome as early as possible.

Many thanks to the girls with Turner Syndrome and their families for your time and for being so open. Thanks also to Arlene Smyth, for imparting some of your considerable knowledge on Turner Syndrome over the phone!

Esther Godfrey

A Project Studying Spatial Awareness

Problems with spatial awareness affect many women with Turner's Syndrome, although it appears that although we are aware of this, following from initial research, there are not a lot of studies exploring this.

Therefore I would like to invite you to participate in my third year project on the issues that many girls with Turners have when it comes to spatial awareness in order to fully understand the issues that you may face in your everyday life.





If you live in either London or Hull I would be forever grateful if you would be willing to take part in the project.

It is completely un-invasive, pain-free, and would only require, at the most, an hour of your time. Please feel free to contact me for any further information.

Marcia Tettey
19 Melbourne Street
Hull
North Humberside
HU5 2ET
07783368444

Extra Child Trust Fund payments for Disabled Children

From April 2010 the government will start to make extra payments into the Child Trust Fund accounts of disabled children. The extra payment will be £100 per year, or £200 per year if a child is on the care component of Disability Living Allowance at the highest rate.

Will all disabled children receive these extra payments?

No. In order to qualify for an additional payment from the government your child must have been in receipt of **Disability Living Allowance (DLA)** at some point in the previous year. In addition, only children born on or after 1st September 2002 have Child Trust Fund accounts.

My child gets DLA. What steps do I need to take to ensure my child receives these extra payments into their account?

The government expects to automatically identify those children who have both DLA and a child trust fund and will then make a payment directly into each child's account. Parents will receive a letter telling them once a payment has been made.

When will my child be able to get the money in their account?

A child must normally wait until they reach 18 years of age to access the money in their account. However if your child has a terminal illness and their death could be reasonably expected within six months, you can get early access to buy things that your child needs.

Phone the Contact a Family helpline for further information (freephone 0808 808 3555).

Editor's note* Thanks to Contact a Family for this helpful article

TSSS Goodies

A full list of the fantastic TSSS goodies available from the Society can be obtained from TSSS office.

TSSS Publications

A full list of all publications available from the Society is available from TSSS Office.

Diagnosing TS Booklets

This excellent booklet has been sponsored by Ipsen to help improve diagnosis of TS and goes hand in hand with our "The Three Tanners Appeal" copies are available from the office to be given to your GP or Paediatrician. We really appreciate being able to have such a booklets to help doctors with the difficult tasks of diagnosing TS. We are very grateful to Ipsen for their support.

We also have little cards to encourage diagnosis which you can also pass to your health professionals. Don't forget the Health Checks Lists are still available from the office too.

0845 Contact Number

The members' telephone contact number for the TSSS is **0845 2307520**. Use it! It is cheaper!





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

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Thank you to all contributors to Vol 4: Issue 6 of ASPEC TS the Newsletter of the Turner Syndrome Support Society. Printed by Harlow Printing Ltd www.harlowprinting.co.uk
Contributions can be mailed to the TSSS office for the attention of the new ASPEC TS Editor Joy Taylor, emailed to joy@tssuk.org.uk or emailed via the TSSS office.

Deadline for next issue is 1st May 2010

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