

UKTS update - APPG, Infected Blood, Zoe's Nutrition Corner, Fundraising and more

Happy Tuesday,

First of all, we would like to say a big thank you to UKTS Ambassador Sajid Hussain and also to a long-standing great supporter and friend of the UKTS, Charalambos Loizou from Cyprus who organised birthday fundraisers on Facebook and raised £818.00. We are very grateful for all donations.

This week we have news of our APPG, another recipe from Zoe and so much more, we hope you enjoy reading our update – please do get in touch we love hearing from you.

- **APPG**

We had a virtual AGM for the All Party Parliamentary Group (APPG) for thalassaemia. Our work for this upcoming year will be focussed on:

- 1) Addressing the inequalities and inconsistencies in thalassaemia care across the UK
- 2) Addressing the issues people with thalassaemia are facing with DWP for Personal Independent Payment etc
- 3) Research into gene therapy and other developments for thalassaemia
- 4) Addressing the unfairness of Prescription Charges for adults with thalassaemia

UKTS needs you to get involved with us to fight these inequalities! Will you help us champion this cause? Please write to your MP and ask them to join the APPG.

Chair of the APPG is Bambos Charalambous (Labour MP for Enfield Southgate)
The Vice Chairs are:

- Bob Blackman (Conservative MP for Harrow East)
- Feryal Clark (Labour MP for Enfield North)
- Alberto Costa (Conservative MP for South Leicestershire)
- Judith Cummins (Labour MP for Bradford South)
- Barry Gardiner (Labour MP for Brent North)
- Fabian Hamilton (Labour MP for Leeds NE)
- Kate Osamor (Labour & Co-op MP for Edmonton)
- Taiwo Owatemi (Labour MP for Coventry NW)
- Catherine West (Labour MP for Hornsey and Wood Green)

- **Patient, Loved ones and Health Care Professional Stories**

We are looking for your stories and experiences- whether it be the good, the bad or the funny! We hope you'd share some of what you've been through or going through so we can help support you or put you in contact with someone who can help.

Sharing your story will also help others realise that they aren't alone, that others have been in similar challenges and made it out alive. Sometimes, that is all someone needs to get through a tough time; knowing that they aren't alone.

Tell us about school, university life, career, home life, chelation drama and for health care professionals tell us about some of the challenges you face – we would love to hear some of the reasons people with thalassaemia give you for not taking their medication! We would also love to see your pictures from things you enjoy doing, having transfusion or even when taking your iron chelation medication. Will you help be the sunlight for someone who is facing a hurricane?

Also, have you met someone in the thalassaemia community who has inspired you? Why not share that experience with us.

Let's get talking and create a closer network of support!

- **Infected Blood Inquiry**

The autumn hearings are due to commence next week. In line with the Inquiry's [Statement of Approach](#) on the questioning of witnesses, please send any suggested questions or lines of questioning (together with any document references) in advance and no later than seven days before the witness gives evidence. Questions should be submitted in both PDF and Word format.

The witnesses and presentations will relate to haemophilia centres, apart from the first witness who will be Lord David Owen on Tuesday 22 September.

The Inquiry has recently disclosed to Relativity the written statements and exhibits of:

- Lord David Owen (supplementary statement)
- Dr Brian Colvin
- Professor Ian Hann
- Professor Peter Collins

See here for the latest news: <https://www.infectedbloodinquiry.org.uk/news>



Hi guys, it is Zoe and I am back with another recipe!

This week I have a feta salad for you that is simple yet nutritious and so delicious! It has been slightly altered from the traditional recipe to cater to your nutritional needs.

Image credit: Steve Brown



Feta Salad

This is a great alternative to salads that consist of tomatoes, peppers and other vegetables that are high in vitamin C (increases iron absorption).

- ▶ Cucumber and red onion are lower in vitamin C
- ▶ Feta cheese is high in calcium which is essential for strong and healthy bones. It also reduces iron absorption
- ▶ Olive oil is high in vitamin E which plays an important role in the immune system and prevent heart is disease

Making small adjustments to your salads can make a difference and will be more beneficial to your health in the long run.

Little fact: While Vitamin C is great for immunity and you should have lots of this in your diet, it can increase iron absorption from the gut. Vegetables like tomatoes and peppers are higher in vitamin C and we suggest that you consume these with foods that are lower in iron like chicken, fish etc.

If you are consuming foods that are higher in iron (like spinach or red meat) we would suggest you try our altered recipe for maximum health benefits.

In this week's recipe, Vitamin C rich foods (tomatoes and peppers) have been substituted with cucumber and red onion. Also, the yummy feta cheese is high in calcium which reduces iron absorption and strengthens your bone density! Bye bye Osteoporosis!

Please note that these substitutes and changes are only for those with thalassaemia major or intermediate not for those with trait or iron deficiency.

If you have any nutrition related questions or suggestions of areas you want more information on, please don't hesitate to email me at admin@ukts.org. Enjoy!

- **Fundraising to improve patient care (Veins!)**

Our team at UKTS has been hosting brainstorming sessions and discussions to identify new ways / ideas which would improve patient care/ quality of life. One major problem identified by most during every visit was the problems encountered finding viable veins. Most patients had to be cannulated several times each visit / had nerve damage resulting from having to tolerate the cannulas even though it was immensely painful from the start of the transfusion just to avoid more cannulation attempts.

We have now identified two possible solutions:

- **Sonovite IVIZ ultrasound machines**

This is an expensive but effective way to prevent multiple attempts as the machine provides the user with a clear picture of the veins.

- **Air Glove**

This is a much cheaper option. How it works is the patient is provided with a disposable plastic long sleeve glove, which is connected to a machine using hot air to warm the arm/ help the veins to pop up.

We are now trying to arrange access for both machines to be demonstrated/ assessed as to whether they can be of use/ helpful to the patients and staff alike. Meanwhile we have already started a fundraiser and would like to encourage everyone to help us achieve our goal.

What do you think? It will be great to have your feedback!

A huge thank you to everyone who has donated or who has suggested fundraising ideas please keep them coming.

Do you own or know of a local business who would be interested in sponsoring a machine for their local hospital? Please let us know.

Remember the following options

- Go Fund Me – please share our Go Fund Me page with friends and family for direct donations <https://gf.me/u/yg8gdi> (**£180 has been donated via this page so far**)
- Shopping – please shop via Easy fundraising or Amazon Smile to raise funds at no cost to yourself.

The easyfundraising App is the easiest way to raise money for UKTS when you shop on your mobile. It's completely FREE and available on iOS and Android, so please get it now to make sure you don't miss out on any donations for us!



Visit: <https://www.easyfundraising.org.uk/easyfundraising-app/>

You can find our easyfundraising page here:

<https://www.easyfundraising.org.uk/causes/ukts/>

- **Royal College of Pathologists**

Earlier this week, we met virtually with Dr Shubha Allard (Consultant Haematologist - Barts Health NHS Trust and NHS Blood and Transplant) and Penny Fletcher (Public Engagement Manager @royalcollegeofpathologists) to discuss ways in which both organisations could support each other.

We are very excited to be collaborating with @royalcollegeofpathologists on educational materials on [#thalassaemia](#) within the college and externally in schools, colleges etc.

We have a lot planned so look out for it soon!

- **Masks/face coverings- Update!**



We are so happy to announce that we now delivered our care packages for patients which include a copy of the magazine, membership form and a UKTS branded logo. We have also sent copies of the UKTS standards of care for adults and children with thalassaemia, colouring books, story books and other information so please ask your teams!

We delivered to 61 hospitals in total:

Addenbrooks, Alder Hey Liverpool, Bedford, Birmingham Children's, Birmingham City, Bradford Adults, Bradford Children's, Buckinghamshire, Cardiff, Coventry, Croydon, Derby, East Lancashire, Glasgow children's, Glasgow royal infirmary, Great Western, Guys and St Thomas, Homerton adults, Homerton children, Hull and east Yorkshire, Imperial College, James Cook, Kings College, Leeds Children's Hospital, Leeds St James University, Leicester Royal Infirmary, Lewisham, Lister, London North West, Luton and Dunstable, Manchester Children's, Manchester Royal Infirmary, Milton Keynes, New cross hospital, Newcastle, Newcastle children's, Newham Hospital, Norfolk and Norwich, North Middlesex, North Staffordshire, Northampton, Nottingham Children's, Nottingham hospital, Oxford adults, Oxford Children's Hospital, Queens Elizabeth Hospital Woolwich, Queens Hospital, Royal Berkshire, Royal free, Royal Liverpool, Royal London, Sheffield, Sheffield Children, Southampton University Hospital, St Georges Hospital, University College London, University Hospital of Bristol, University Wales, Wexham Park, Whipps Cross and Whittington Hospital.

Remember to fill out the membership form and send it back to us and of course send us a picture of you in the masks, we want to see your selfies!

You and your loved ones can also buy masks and support the UKTS! Our masks are on sale for £6 for one or £10 for two! Get in touch with us if you would like to purchase 1, 2 or all 😊.

- **GDPR**

We are striving to ensure that we stay in contact with all of our members and would encourage everyone to complete a membership form. This ensures that we adhere to GDPR guidelines and only hold the information you would like us to have. It also helps us to plan events and activities relevant to our members.

Forms can be found on our website here: <https://ukts.org/member/>

Kind regards,
Teresa

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Registered charity no. 275107

Please follow the link to donate to us: <https://www.paypal.me/teamukts>

For our latest magazine: <https://ukts.org/magazine/>

National Thalassaemia Day (UK) on October 19th annually



<https://www.easyfundraising.org.uk/causes/ukts/>