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News from the Office



Cheers to a happier New Year!

What a year this has been! We are hoping and praying that 2021 will bring better things for us all.

I have missed seeing you at clinics this year and I hope it won't be too long before I see some of you again. I continue to attend the Clinic MDT meetings through Microsoft Teams when I get the opportunity to discuss the service and bring the Team up to date with what the Support Group is doing.

We continue to organise film on the windows and cars for our patients and provide new patients with UV metres. If you have not had film put on your windows, please do not be afraid to ask.

Our main goal at the moment is to run Owl Patrol which will take place on 13 & 14 February 2021. BBC Children in Need have been very generous and are allowing us to spend our grant to deliver a virtual Owl Patrol "Camp in Box". As it is Olly's 20th Birthday, the event will be party themed. We aim to get a box to every family and volunteer so that you will have all that you need to take part in the weekend. The sign up form and programme are on pages 5 & 6. We would like to see as many of you as possible especially those campers and volunteers who haven't been to Owl Patrol for a while. As the event is virtual you will be able to choose which sessions you wish to attend.

For those of you abroad, you are also very welcome, although we cannot guarantee to send a box to you, but we will let you know what you need to take part.

I'd like to take this opportunity to raise a glass to you all, and to send you best wishes for the New Year

Sandra Webb, Trustee

Stay safe!

In the Newsletter this month, there is the sign up for the Narrowboats project (P7) which has been postponed until 2021 and Owl Patrol 2021 (P5)

Fundraising

Is there something you can do to fundraise for us too? It doesn't have to be a sporting event, it could be a cake sale, coffee morning, charity quiz, there are lots of ways to have fun and raise money for the XPSG at the same time! Even raising small amounts of money, helps us to help our XP patients, so please have a think about how you could help us to help you. If you have any fundraising ideas or need help in organising an event, please contact Flora at flora@xpsupportgroup.org.uk or fundraising@xpsupportgroup.org.uk

RAISE MONEY WHEN YOU SHOP!

When you shop @AmazonSmile, Amazon will make a donation to XP Support Group. So please keep us in mind when you shop online! <https://smile.amazon.co.uk/ch/1075302-0>

Shop online by registering with <http://www.easyfundraising.org.uk/causes/xpsupportgroup> which adds a link your tool bar and enables you to shop at over 2,000 online retailers including John Lewis, Argos M&S, eBay, Tesco Direct, Debenhams and Apple. Registration is free and very easy to do.

The XPSG is entirely dependent on fundraising and grants to be able to provide patients with UV meters, travel and accommodation expenses when attending the clinic, as well as paying for cars and houses to be protected with UV film.

THANK YOU

We would like to say a special Thank You to High Wycombe Lions who have supported us over the 22 years of our existence. Each year they organise the collection of our families to and from Owl Patrol and have chosen us one of the charities to benefit from their Christmas collection. The Lions have closed the High Wycombe group and chose the XP Support Group as one of the charities to benefit from the disbursement of their outstanding funds. We are truly thankful for the £650.

Thank you too the Hussain Family for the very generous donation of £400.

We would also like to say thank you to those who donate to us regularly, some with their names and others anonymously. Thank you for your continued support

FUNDRAISING ACTIVITIES

Did you see the BBC Children in Need film featuring Hazel and Owl Patrol during Autumn Watch? If not, you can take a look here at:

<https://www.bbc.co.uk/.../m000.../autumnwatch-2020-episode-7>

Hazel's next goal is more fundraising for the XP Support Group – she is planning to climb Ben Nevis in early Spring 2021, if you wish to donate go to:

<https://www.justgiving.com/fundraising/hazel-avery1>

26K Winter Challenge

A group of local individuals had trained to run the Ragnar relay in the Forest of Dean in June, which was cancelled. The team continued to train and came up with an idea to keep them motivated over the winter months by doing 26,000 km with their friends and colleagues. The group raising funds for us now includes participants from the US, France, Germany, India and the Netherlands participating taking us up to 28 members in total. You can support the group at <https://www.justgiving.com/fundraising/26000test>

The XP Support Group has been chosen by Covance of Maidenhead as their charity for the year and they are raising money to fund future Narrowboat trips for our families. Here is a report from Shivani about what they have been doing to help us so far.

Here at Covance, we have been raising money for the XP Support Group as part of the Intern Charity Project – we have had to adapt to the current pandemic situation and conduct all of our fundraising events virtually. In September, we kicked off our fundraising with a 'Guess Who's Behind the Mask' competition, where various colleagues were pictured wearing Covid face masks.

For Halloween, we ran a Pumpkin Carving competition, where colleagues sent in their pictures and our judges picked winners in 3 categories - the Scariest, Funniest and Most Creative Pumpkins. We are currently collecting entries for our Christmas Decorating Competition, where colleagues are putting their baking skills to the test to make their best Christmas-themed creations. So far, we have raised the impressive amount of £617 for the XP Support Group, and we will continue to raise even more into the new year with more exciting events!

Our First Virtual Event!

Guess Who's behind the Mask!
Only £1 to enter!



Prizes
to be won!



Update from the XP Clinic Team

The National XP Service – team report December 2020



Greetings to all, from the XP team, here in London

Since our last update, despite Coronavirus and various lockdowns/different tiers around the country, we have continued to run the XP clinics and have managed to see some of you face to face and others virtually. We know virtually is not ideal, but hopefully you have continued to feel supported by us when it comes to anything XP related. It is still important that if any of you notice anything different on your skin, you let us know as soon as you can. We will always be happy to see you either in London or we can arrange for a dermatology appointment local to where you live.

We have been gathering feedback on how both you and we have found the virtual clinics. There have been a lot of positives, less time spent travelling, taking less time off work/school, still being able to see all clinicians and opportunity to ask us questions. Then the negatives, harder to check the skin especially if there is a lesion that is being monitored, not such a thorough physical examination possible especially if we are the only centre that you get seen at for your XP, no access to IT or skills in how to use it. Moving forward we foresee virtual appointments will have a role in our service depending on want or need for some appointments.

In October we hosted the European XP symposium, set up by our own Bob Sarkany. This event now in its fifth year is usually an optional extra added to a big dermatology conference, therefore primarily attracting European Dermatologists. An advantage this year, with holding it virtually, was that it opened it up to a much wider audience and was keenly attended by 67 delegates. Doctors from not just Europe but from around the world, along with XP support groups, also from around the world, were able to discuss all things XP related in either joint sessions or designated specialist sessions. Highlights from the clinical sessions were case studies about XP that others countries were finding challenging that all the doctors could discuss resulting in expert advice hopefully for the benefit of that particular patient.

As the XP children's nurse, I have now reduced my hours to 22.5 per week. We will be replacing the extra hours left of the full time job in due course so watch this space for any news. In the meantime, any time I am not in the office, I will leave a bounce back message on my email and answerphone message to say who to contact in my absence. Or if you prefer to leave a message, I will get back to you as soon as I can.

As always we are on the web at www.gstt.nhs.uk/XP.

We all hope you have a good Christmas and a Happy New Year
Sally Turner, on behalf of The XP team



Update from Teddington Trust

We hope that this finds you and your family well as we come to the end of a rather extraordinary year!

We greatly missed not hosting Teddington's BIG Adventure Sleepover this Autumn but look forward to hopefully being able to bring us back together for another dose of high-octane fun in 2021. We hope to see you there.

It has been a year of very little fundraising as we have respected our community and followers by not asking for support, in recognition that many are financially impacted by the current pandemic. This of course, will have a significant impact on our outlook for the year ahead and we hope to be able to make up lost ground with some creative ways to boost funds next year. Until then our fundraising book, The BIGGEST Book of Yes, continues to do well on Amazon bookstore and we benefit from 100% of all proceeds from each and every book sale which is wonderful.

If you are looking for a last-minute gift for a would be adventurer you can get your copy here: <https://amzn.to/37p1yO5> or by searching for The BIGGEST Book of Yes on Amazon.

Thank you to everyone who submitted their questions to us for answer by Clinuvel regarding their DNA repair therapy currently under clinical trial. As soon as we have the collated and full responses we will circulate this to all for your information.

Until then, wishing you and your family a safe and love-filled Christmas holiday, and here's to brighter days on the horizon in 2021.

With much love

Nicola Miller and all at Teddington Trust



With your help
in the last 7 years we have...

Across the UK & Globally

- Shipped nearly 1,000 patient packs (containing FREE UV protective hats, gloves and film)
- Funded and dispatched 12 vented cooling hat trials within the UK
- Created, funded and dispatched 80 schools packs to UK schools (educating in excess of 80,000 UK pupils on rare disease)
- Supported 15 families with blue badge applications
- Supported over 20 families with DLA and PIP applications including preparing all paperwork for appeals

Did you also know?

- In the last 7 years we have dispatched Little Ted bears and story books to over 650 children with XP in 6 of the 7 continents of the world!

thank you

We couldn't do it without you!!!

www.teddingtontrust.com
@TeddingtonTrust

Owl Patrol
13 & 14 February 2021
This is subject to change based
on restrictions due to Covid-19



Owl Patrol turns 20! Time to celebrate!

Owl Patrol will be back in 2021 but not as we know it. We cannot ignore that the current pandemic has meant we have to change the way in which we do things. Owl Patrol 2021 will be virtual and take place on 13 & 14 February and will be held on-line. We are disappointed that we will not be able to have our families at St Katharine's but we do hope you will like our new concept.

This year you will have "Camp in Box". All UK campers will receive a package at home before camp starts containing all you need to experience our very first virtual camp. We will have lots of activities for all ages including adults, and all will be on a Olly's Birthday theme and will be led by the Volunteers by Zoom who will be based at St Katharine's.

For campers from abroad, we will provide you with a list of what you will need to participate.

We will have our usual sessions and workshops with the XP National Clinical Team. Please see the programme on the following page

To take part in camp you will need access to a broadband connection and laptop or tablet. If you do not have access it is very important that you let us know as we are working to ensure that all UK families are able to participate.

If you would like to take part, please complete the application form and return by 31 December 2020. You can still apply after this date, but we cannot guarantee you will receive our box in time. You can use the form below or apply on line at <https://xpsupportgroup.org.uk/owl-patrol/>

Name of XP Camper _____ Age _____
 Address _____
 Town _____ County _____
 Postcode _____ Country _____
 Telephone (include country code if outside UK) _____
 Email _____
 Parent/Guardian _____
 Do you have Broadband access to the internet YES/NO
 Do you have access to a computer/laptop or tablet YES/NO

Other family members who will attend (please provide names and ages for those under 18)

Owl Patrol Programme

Saturday 13th February 2021

09.30	Wake up session
10.00	Welcome & Slideshow
10.15	Balloon modelling/song writing
10.15	The Science of XP Professor Alan Lehmann
11.15	Break for coffee/tea
11.30	Family Craft session- Pottery
12.30	Lunch
13.30	Family activity
	Decorate Biscuits
14.00	XP Clinic – Virtual, actual or hybrid, how can we improve the experience Workshop for adults & kids Led by XP Team
15.00	Break for afternoon Tea See “Camp in a Box”
15.45	XP International - News of our International collaboration with groups abroad
15.45	Craft- Owl Weaving
17.00	Break for Dinner
18.00	Murder Mystery/Puzzles
19.30	End of Session

Sunday 14th February 2021

09.30	Wake up session- yoga
10.00	Decorate Pottery
11.00	Break for tea/coffee
11.15	Negotiating Personal Independent Payment (PIP) Speaker TBC
11.15	Kids workshop with XP Team
12.15	Break for lunch
13.15	Update of the Visor project Patricia Grocutt, Kings College London
14.15	XP International News from Clinicians abroad
14.15	Kids craft/activity
15.15	Break for tea/coffee
15.45	Family Quiz with Prizes
16.45	Awards & Lean on Me
17.30	End of Camp

Visor Project Update

This is an end-of-the year summary of the progress on the Visor Project and where we go next. The COVID-19 pandemic prevented us from sending out prototype visors for people to try on in their own homes and provide us with feedback via MS Teams. We have therefore redoubled our work on manufacturing prototype visors for people to review. We are collaborating with The Manufacturing Technology Centre, Coventry to do this and have a grant application under review. We will know the outcome around February 2021. In January we will submit another grant application, as we cannot be certain the first one will be successful.

During the Visor Project we have collected a lot of information on what people are looking for from a visor. We have developed performance indicators for you to judge commercially manufactured visors. Some of you helped to check the accuracy of the indicators using the TELER online Delphi system, and thank you for this. We have an economic model to determine the costs and value of providing the visors via health services such as the NHS. We will take these outputs forward to the next phase. We want to assure you we are very committed to producing professionally manufactured visors

The King's Team would like to thank you all for the wonderful support you have given us. We also want to thank the National Xeroderma Pigmentosum Service Team and the Rare Disease Centre Staff, the XP Support Group and Teddington Trust for their support in enabling us to conduct this research, as well as the National Institute for Health Research for funding the project.

With our very best wishes for a Happy Christmas, a peaceful end to the year, and a very much better year ahead. Trisha, Tanya, Sangeeta, Yan-Shing.

Narrowboat Trips 2021

Due to the Covid-19 restrictions this event is postponed until further notice. You can still register your interest by emailing: sandra@xpsupportgroup.org.uk

We will be running family trips hopefully from Easter 2021.

There is maximum of 8 places available for each trip. The weekend is free of charge and participants will only require pocket money for things they wish to buy when they stop at the supermarket. We will also pay travel expenses. You will be accompanied by 2 volunteers from Hillingdon Narrowboats. All volunteers are DBS checked. For more information about Hillingdon Narrowboats, please see their website at <http://hillingdon-narrowboats.org.uk/index.php/en/>



In Memoriam

It is with great sadness that we announce the passing of XP Patient Angela Smart on 7 December. Angela and her husband Keith have been supporters of the group since we started. For those that knew her funeral will be streamed live on 29 December at 12.15 on www.obitus.com. Please contact sandra@xpsupportgroup.org.uk for the username and password

XP on TV

As well as Hazel on Autumnwatch (see page 2), our own Dr Emma Craythorne was featured on Bad Skin Clinic with XP patient Livvy. To watch the episode, please visit

<https://www.discoveryplus.co.uk/show/the-bad-skin-clinic?idp=Sonic&responseCode=212>

Dates for your diary

2021

13 & 14 February – Owl Patrol, St Katharine's Parmoor (see page 5 & 6)

28 February – Rare Disease Day

11–15 November – 2nd International XP Patient Medical Conference and Camp, hosted by the XP Family Support Group, in Minneapolis, USA

Clinic dates 2021:

Children's: 22 January, 26 February, 26 March, 23 April, 28 May, 23 July, 24 September, 22 October, 26 November

Transition: 29 January, 30 April, 30 July, 29 October,

Adult: 8 January, 12 February, 12 March, 9 April, 14 May, 11 & 25 June, 9 July, 13 & 27 August, 10 September, 8 October, 12 November, 10 & 17 December.

Office closures

Please note the office is no longer manned and we have changed our telephone number to 01494-890981. To contact Sandra Webb please email:

sandra@xpsupportgroup.org.uk General enquiries should be sent to info@xpsupportgroup.org.uk

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