

1st International XP Medical Conference & Camp

London 9-12 February 2018

CONFERENCE REPORT





WELCOME

In 2015, Michele Milota (XP Family Support Group, USA), Maryna de Beer (XP Society South Africa) and I were at a conference in Vancouver for Leaders of Patient Support Groups for Dermatological conditions. At the end of the conference we all felt that we had gained so much that we needed to do something similar for all XP patient support groups, and so the idea grew for the

Conference that we the XP Support Group had the privilege to host for the very first time. We felt it was time that we all came together to share our experiences, so that in the future we can work in co-ordinated way to help XP families across the world.

It was my pleasure to welcome families from UK, USA, France, Germany, Canada, South Africa, Austria, Belgium and Spain. Our speakers came from the XP Clinic in the UK, the National Institute of Health, USA, Institut Gustave Roussy, France, University of Regensburg, Germany and Erasmus Medical Centre, Netherlands.

I would like to take this opportunity to thank Global Make Some Noise, Lady Ryder Memorial Fund, St John's Photodermatology Trust, La Roche-Posay, The British Association of Dermatologist, XP Family Support Group, Enfants de la Lune, Teddington Trust and XP Freu(n)de for the support with grants and sponsorship.

Thank you too to Kentish Town City Farm, the Roundhouse and Hillingdon Narrowboats Association who provided some wonderful outings. To the Beat Goes On, Climate Chaos, Teddington Trust, XP Clinic and Katy Seth from Rock Choir for the excellent workshops.

Most especially I want to say a big Thank You to all our wonderful volunteers without whom, we would not have seen so many happy smiling children and to my sister Angela who helped me plan and make this conference happen.

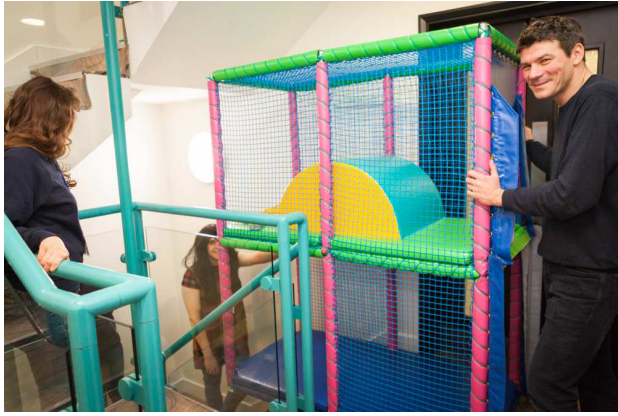
We look forward to the 2nd Conference in Niagara Falls in 2020 and the 3rd in Paris in 2022

Sandra Webb

Founder & Trustee, XP Support Group

Organiser, 1st International XP Medical Conference and Camp

Friday



Preparations started early for our volunteers setting up the Children's Camp. Equipment had to be moved in order to transform two empty conference suites to a Children's adventure playground.

The team were ready in the foyer to welcome delegates and campers. We were all very excited and nervous about all that we had committed to do. Was the programme too busy or had we not planned enough? It was too late to go back.



Friday

Our conference opened with a welcome dinner giving delegates the opportunity to get to know each other.



The theme of our weekend was Music and Dance and after dinner the Children disappeared then to return later to teach the grown-ups Body Percussion. This was a perfect way to break down barriers as no language was required, just the sounds from our bodies.

We would like to extend a special thank you to Ollie from the Beat Goes On for organising both children's and adults workshops.

The evening finished off with Film night



Saturday

Saturday was the day for the presentation of the work from the various groups supporting XP around the world .

Presentations were given by

- Michele Milota, (1) XP Family Support Group, USA.
- Francisco Dominguez Roman, (2) XP Spain
- Alexandra (3) & Christian Moser, (4) XP Freu(n)de die Mondscheinkinder, Austria & Germany
- Maryna de Beer, (5) XP Society, South Africa
- Wafa & Zied Chaabi, (6) Enfants de la lune, France,
- Nicola Miller (7) & Rebecca Stewart (8) from Teddington Trust
- Professor Patricia Grocutt, (9) Research Lead for the XP Visor Project, Kings College London



Saturday

In addition to the presentations, adults continued the music theme and were treated to a workshop by Katy Seth from Rock Choir. To hear the results visit

<https://www.youtube.com/watch?v=1D8zJErK0HI>

The children's programme included an indoor funfair with crafts, a visit to Kentish Town City Farm, and Global Music Station Headquarters





Sunday

This was our Medical day and thanks to a grant from the British Association of Dermatologists we were able to livestream the talks to families across the world. Our speakers came from the UK XP Clinic, The National Institute of Health, USA, Institut Gustave Roussy, France, University of Regensburg, Germany and the Erasmus Medical Centre, Holland.

Powerpoint presentations are included with this report and the links to recorded sessions are also included.

The highlights were that the Scientists and Medical profession are beginning to



Dr Robert Sarkany, XP Clinic UK

believe that gene editing is likely to lead to a cure for XP, but it was impossible to predict a timeframe.

The Ask the Experts session was very interactive with

questions coming from the room and from those watching via the internet.



Dr Hiva Fassihi, XP Clinic, UK



Clinical Nurse Specialist, Tanya Henshaw,
XP Clinic, UK



Clinical Nurse Specialist, Sally Turner
XP Clinic, UK

Presentations available to view please go to

<https://www.youtube.com/watch?v=JpDh5DrhPJQ>



Professor Alan Lehmann, XP Clinic, UK



Professor Alain Sarasin, Institut Gustave Roussy, France



Nurse Debby Tamura, National Institute of Health, USA



Arjan Theil, Erasmus Medical Centre, Netherlands



Dr Monika Ettinger, University Hospital Regensburg, Germany

Presentations available to view <https://www.youtube.com/watch?v=ZE4bPm5kxgw> and
https://www.youtube.com/watch?v=h8NQkMi_BPU



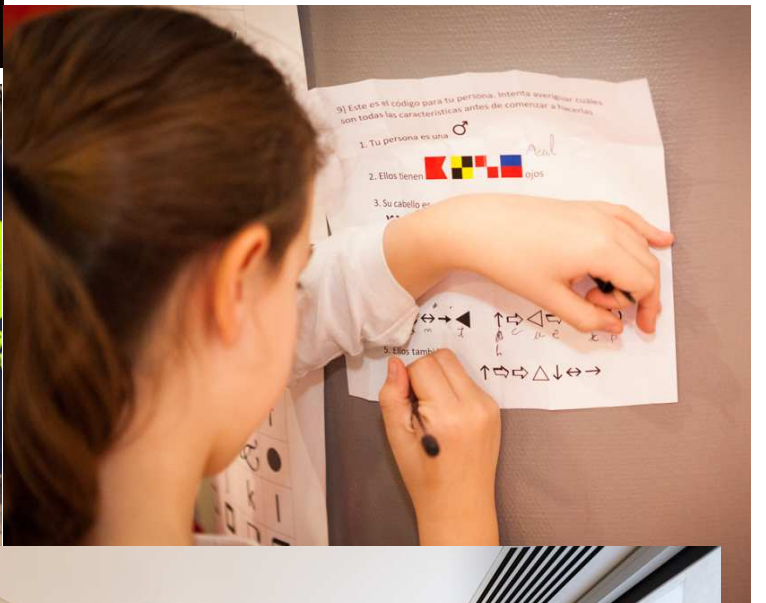
The Expert Panel Q & A Session

Available to view <https://www.youtube.com/watch?v=2FbYxz7hwb4>

Sunday –Children's activities

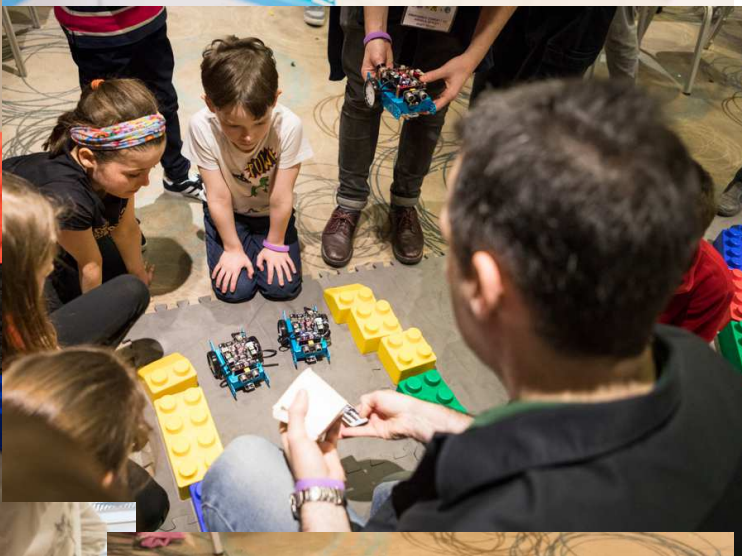
On Sunday the children were kept extremely busy with more Arts & Crafts, a visit to Regents Park Playground, a DJ-ing workshop at the Roundhouse, Science Party, Afternoon Tea, Robot building with a Genetics for Kids workshop run by the XP Clinic Team and Comic Workshop run by Teddington Trust.





Sunday—children's activities





Hillingdon Narrowboats Association (HNA)

Throughout the weekend HNA provided two UV protected narrowboats (Star and Spirit) to give our families the opportunity to enjoy the canal in the Camden area.

Star Sleeps 12 people including a steerer in their own cabin and is suitable for weekend and longer breaks with hostel style accommodation. The main cabin can be isolated to allow XP patients to remove protective clothing.

Spirit Is suitable for day trips and has full wheelchair access (lifts each end, Open Plan interior, accessible toilets).

For detail of availability please visit www.hna.org.uk

Here are some highlights from the weekend



Celebrating 20 years of the XP Support Group

Thank you awards



Thank you Angela & Claude Verley

When we decided to set up the XP Support Group, Angie & Claude showed their commitment by making the first donation. Claude was also the winner of the competition to name our Camp Patrol. Through the years they have arranged fundraisers and visited Owl Patrol. Their weekly Bonus Ball lottery has raised nearly £2,000. They both continue to show their support and were volunteering at camp for the first time. Angie has been our Administrator for the last two years.

Thank you Cathy Coleman and Anna Wasyluk

Cathy and Anna were the designer of the Face visor that our children and adults wear. We worked with the European Space Agency and they couldn't come up with a better idea. We all appreciate what they have done for all our families.



Thank you Alan Lehmann, Arjida Woollens and Robert Sarkany

For our XP Specialist Clinic. The Support group has always had a good relationship with Professor Lehmann. At the very beginning he invited families to visit the laboratories in Brighton to see what happened to their biopsies and he attended our early meetings in the village hall in Prestwood. In 2005 he approached us along with Dr Woollens to see if we would be interested in an experimental Multi-disciplinary clinic at a hospital near Brighton. We arranged for our families to attend and it was clear very

that our patients were very happy with this approach. In 2007 Dr Sarkany moved the Clinic to St John's Institute of Dermatology at St Thomas'. At this stage Doctors were giving their time free of charge. With Dr Sarkany at the helm, along with Alan Lehmann and Sandra Webb, we began the process of applying for funds for a Nationally commissioned Clinic. We were successful and in April 2010, the new clinic opened. Today the Clinic is in its new home at the Rare Disease Centre at St Thomas Hospital. Without the early work of these three individuals, we would not have this wonderful service today.

Celebrating 20 years of the XP Support Group

Thank you awards



Thank You St Katherine's Parmoor

For being the home of the Owl Patrol. We found St Katharine's by chance. In 2000 when Sandra was organising our 1st Auction of Promises to raise funds for our first camp at the venue where she and Steve had held their wedding reception. The Catering manager was very interested in our project, We explained that we had looked at several venues but had not found something suitable. She said she managed the catering at another venue which she thought would be just right for us, she phoned them and a couple hours later Sandra walked through the door

of St Katharine's and knew that we had found our home. The Sue Ryder fellowship who own St Katherine's has also been very generous with grants to the group. Bethan, who accepted the award on their behalf has been with us from the beginning



Thank You High Wycombe Lions

For transporting our Volunteers and Campers to and from Owl Patrol and for their continuing support.

Sandra met Eileen before Owl Patrol, and was invited to speak to a group of Lion's wives about the work of the Support Group and our future plans. Later this group became part of the High Wycombe Lions as they are today. They have raised funds for UV protective clothing, sun cream and to help a Cuban family attend Owl Patrol. At our first Owl Patrol we were asked

how we got people to the venue. We explained that Steve and I had gone backwards and forwards to stations and airports. From that point they took over and now their volunteers go to Heathrow, Stansted, Gatwick and Luton Airports as well as High Wycombe and Maidenhead stations. Eileen who is also an Owl Patrol volunteer accepted the award on behalf of the Lions.



Thank you Alex Wasyluk and Alex Webb

For being the faces of the XP Support Group. Alex and Alex's faces have graced our posters and leaflets. They have appeared on TV several times raising the profile of XP. In 2014 Alex Webb was a member of BBC's The One Show Team Rickshaw riding from Salford to Walford raising over £1,000,000 for BBC Children in Need. Just days before the Conference Alex Wasyluk was featured in a documentary on Channel 5- The Special Needs Employment Agency.

Both Alex's have been volunteers at Owl Patrol.

Celebrating 20 years of the XP Support Group

Thank you awards



Thank you Dirk & Monika Prenting

For finding the Plastic for our face visors

When the British supplier stopped producing the UV protective film, we along with the XP Family Support Group and Freu(n)de die Mondscheinkinder had to find a new supplier. It took nearly a year and we had almost ran out of film when Dirk and Monika found us a new supplier who continues to supply our group with film, free of charge.

Dirk and Moni have stepped down from running the German Group and successfully passed leadership to Alexandra and Christian Moser. Alexandra and her daughter Sarah accepted the award on their behalf.

We also made a further **Thank You award to Caren Mahar** from the XP Society for inspiring all our groups with Camp Sundown.

A week after Alex was diagnosed Sandra met Caren Mahar and from that meeting came the idea of setting up the support group. In 2000 the Webb family were very lucky to attend Camp Sundown. At that Camp Sandra saw on of our own XP children blossom over that week. On her first day, she hardly left her mother's side, before long she was joining in all the activities. Sandra can still remember her showing model that she has made, she was so proud. Sandra knew that we needed something like Camp Sundown in the UK to inspire our children and increase their confidence.



I would also like to say a big Thank You to Sarah and the volunteers for the Thank You Award they made to a very tearful me. My vase now stands very proudly in our living room.

Sandra Webb





Goodbye from all of us and see you in Niagara Falls in 2020

