

Fanconi Hope FA Conference and Family Fun Day Oct 14th 2017 at Twycross Zoo

Dear All,

Thank you for supporting this event. Here is some more detailed information about the day.

Directions to the Conference and the Hotel Venues

The Conference starts with Registration/Coffee at 10.30am at Twycross Zoo Conference Centre, and finishes around 5pm. Those attending the evening meal should then make their way promptly to the Appleby Park Hotel at 6pm.

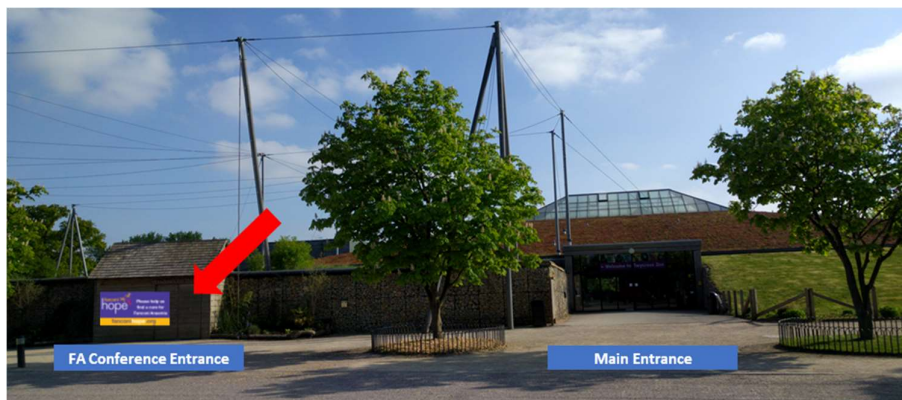
- **Twycross Zoo**, Burton Rd, Atherstone CV9 3PX. Located on the A444 about 4 minutes' drive from Junction 11 of the M42.
- **The Appleby Park Hotel** is located at Junction 11 of the M42. The entrance is just off the start of the A444 opposite the Shell Garage



If arriving by train, you are advised to use Tamworth Station due to better availability of taxis (Acorn Taxis Tamworth 01827 83333). Journey time to the Zoo is around 20 minutes.

Upon Arrival

The Conference Centre is located just inside the Zoo Main Building, but we have our own entrance, to the left of the main Zoo entrance which will be signposted with a Fanconi Hope poster (See red arrow below).



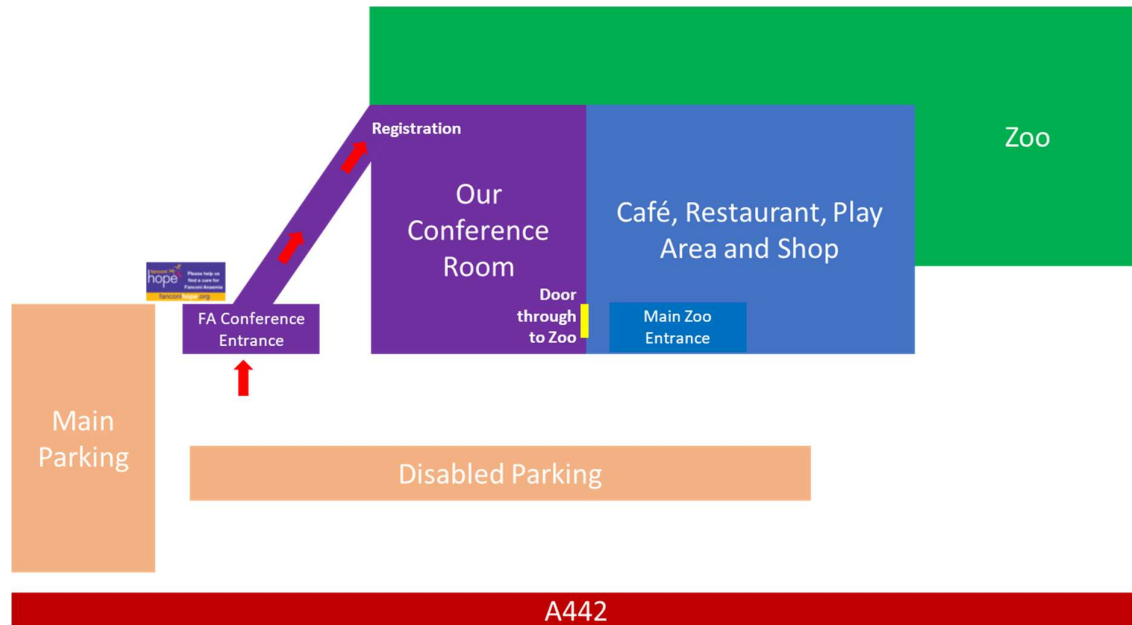
Twycross Zoo Entrance

Please could everyone use this entrance so that you can be given name badges and any Zoo and Play Area passes that you have already requested. Lanyards for name badges are colour coded:

- White – For FA families
- Blue – For health professionals
- Purple – For Fanconi Hope Charity helpers

Refreshments should be available in the Conference Room from 10am and again at 3.30pm.

Lunch will also be provided free of charge in a sectioned off area adjacent to the Conference Room



Zoo Layout

Visiting the Zoo itself

For those wishing to visit the Zoo itself and the Play Area, access can be gained through the Conference Room and then via the door on the opposite side of the room. With your Zoo/Play Area tickets/bracelets you may enter and exit the Zoo/Play Area as much as you like. Of particular interest may be the following scheduled Zoo events:-

- Penguin Parades at 12.30pm and 3.30pm
- Meerkat Feeds at 3.15pm

You can find a map of the Zoo here: <https://twycrosszoo.org/visit-us/zoo-map>

Evening Meal at the Appleby Park Hotel

If you have booked in for the evening meal, please proceed to the hotel straight after the Conference as the meal is set for around 6pm. Complimentary soft drinks will be provided upon arrival, and you are welcome to purchase alcoholic drinks at your own expense throughout the evening at the bar. We have arranged a 2 course buffet meal in a private dining room for the evening, which is located adjacent to the bar, which is straight ahead of you when you enter the hotel. For non-residents the bar is open till 11pm.

Agenda

The day is structured to give as much time for interaction with specialists and other families as possible. As well as our presenters, who you will be able to talk to during the presentations and more informally we have a number of nurses who work in FA clinics present from across the UK who will be happy to chat.

A number of 30 minute sessions will be presented by a set of experts from across the UK covering a wide range of relevant topics, including descriptions of the condition itself, current Fanconi Anaemia treatments, the biological and genetic aspects of FA and about bone marrow transplantation.

There should be plenty of time for questions and discussion throughout the day both during the 30 minute sessions and in the breaks.

A key aspect of the day is an introduction to the Fanconi Hope-funded "*Late Effects of FA*" study run by Dr Stefan Meyer and others present on the day. This study into the long term health of patients with FA and best practice treatment requires contributions from as many people affected by FA in the UK as possible. This event is therefore an ideal opportunity also to meet Beth Lee, who is acting in a liaison role between the Study, the Charity and UK FA patients and families, and learn about the aims and objectives of the study and how you can participate. Beth has a wealth of experience working with families with FA and will share some of this experience and will include some of the softer issues in dealing with having FA.

We are pleased to have a representative from the UK part of the Europe-wide *Gene Therapy for FA trial* which is now under way.

Some of you may know, or have heard of, Ralf Dietrich and Dr Eunike Velleuer who have travelled worldwide meeting FA patients whilst undertaking their *Early Cancer Detection* study. As well as presenting at our event, they invite you to participate in their study by giving mouth brush samples during the Conference event or at the hotel afterwards. You can read more about this important study in the attachments to this email. A Consent Form is also attached, which will require to be signed before any testing can take place, so it is worth reading this before the event itself to save time. You can see more about the study [here](#).

We end the day hearing about one family's experience, from both the mother and the daughter's perspective, in coping with FA from diagnosis, through bone marrow transplantation to living with the condition in late teens.

We are pleased also to have a representative from the [Contact \(Contact a Family\)](#) charity present. She will have a stand at the back of the Conference Room throughout the day and you are encouraged to have a chat to learn the many ways in which this charity can support you.

The day will also be an opportunity to learn more about the work of Fanconi Hope and discuss how you may be able to contribute.

10.30 - 11.00	Arrival, Registration and Coffee	In Conference Room
11.00 - 11.20	Welcome and Introductions	Bob Dagleish , Secretary, Fanconi Hope and FA parent
11.20 -11.50	Introduction to Fanconi Anaemia, clinical management and long term health of patients	Stefan Meyer , Department of Paediatric Haematology and Oncology, Royal Manchester Children's Hospital, Department of Paediatric and Adolescent Oncology, Young Oncology Unit, The Christie NHS Foundation Trust, Manchester.
11.50 - 12.20	The Genetics of FA – what you need to know.	Marc Tischkowitz , Department of Medical Genetics, University of Cambridge, Addenbrooke's Hospital, Cambridge
12.20-12.50	Developments in Gene Therapy for FA	Philip Ancliff , Institute of Child Health, University College London
12.50 - 14.00	Lunch	
14.00- 14.30	Biological aspects of FA	Dr Nigel Jones , Institute of Integrative Biology, University of Liverpool
14.30 - 15.00	Bone Marrow Transplantation	Josu de la Fuente , Department of Paediatric Haematology, St Mary's Hospital, Paddington, London
15.00 - 15.30	Coffee Break	
15.30 - 16.00	Early cancer detection study: Reducing the Burden of Squamous Cell Carcinoma in Fanconi Anaemia	Dr Eunike Velleuer , Heinrich Heine University, Dusseldorf, Germany, and Ralf Dietrich , Executive Director and Family Support Coordinator, German FA Support Group
16.00 - 16.30	Living with FA: Family issues / late effects and how to interact with Beth and the Late Effects Study	Beth Lee , FA Nurse and Fanconi Hope Liaison, Royal Manchester Children's Hospital
16.30 - 17.00	Living with FA: A family perspective	Louise Parry , Treasurer, Fanconi Hope and FA Parent, and daughter Amy Parry who has FA
17:00 – 18:00	Travel to Appleby Park Hotel for those dining	Please note that there is the similarly named Appleby Inn before you get to our hotel.
18.00	2 Course Buffet Dinner	