fanconi hope

newsletter

Fanconi Hope Charitable Trust | Charity Reg No. 1126894 | December 2020

The Year in Review - An update from Bob Dalgleish, Fanconi Hope Chairman

First of all, welcome to our 2020 Newsletter! The year did not exactly turn out as planned due to COVID 19, but there have been some positive developments, such as the ability to communicate now with families across the UK on Zoom, which we have done on several occasions as have many other FA organisations around the world. Although these can't replace face-to-face meetings they have resulted in wider audiences. We expect many FA events in future to be a mix of real and virtual to get the best of both worlds.

Despite our usual major source of funds through sponsored events on JustGiving etc clearly not happening, we have continued to receive donations, large and small, from a variety of sources, which have allowed us to continue our work.

In conjunction with our Netherlands counterpart Patient Support Group, we have helped set up a European umbrella organisation for FA called FA Europe, bringing together clinicians, researchers, patient support groups and patients with the ultimate aim of achieving equal access to optimised care for people across Europe affected by Fanconi Anaemia. This has become especially important for the UK since the impact of Brexit is causing many of the existing medical links to be severed.

We have been liaising closely with the US-based Fanconi Anemia Research Fund (FARF) to ensure we don't duplicate effort both in the UK and across Europe. Our number one priority, as it is of FARF (and many other countries around Europe), is to improve cancer care for people living with FA. FARF have a number of important initiatives which have started up to support this, in which we expect also be involved.

Our Fanconi Hope contribution to improving cancer management is in the optimisation of Proton Therapy treatment for FA patients with solid cancers through our project. Thanks to your generosity we have now been able to fund this 3 year research project at Manchester University .

Our plan to hold a joint UK-Netherlands Adults weekend this year was thwarted by COVID but the event has now been rebooked for September 2021. Let's hope that this won't have to be postponed further - It looks like a lot of fun!

Sadly this year we had to say farewell to Joanne Smith our longest surviving UK FA adult. She will be sorely missed. Read more on Page 9.

It just remains for me to thank you all, on behalf of the team at Fanconi Hope for your continued support and to wish you all the best for 2021.

Chairman

Look out for our next COVID-19 Zoom Webinar with Professor Josu de la Fuente on 5th January at 7pm! Joining details will be posted soon in our Facebook Group, Twitter and Instagram.

FA Europe Organisation starts up in earnest

In 2019 Fanconi Hope and our equivalent in the Netherlands, the FA Workgroup of the VOKK, jointly submitted a proposal to the US-based Fanconi Anemia Research Fund and subsequently received a $10,000 grant from them to help set up a European Umbrella Organisation for FA. This is now all the more important for the UK since, as a result of Brexit, the UK is now disconnected from many of the pan-European initiatives that our FA consultants and researchers have been deeply involved in for many years.

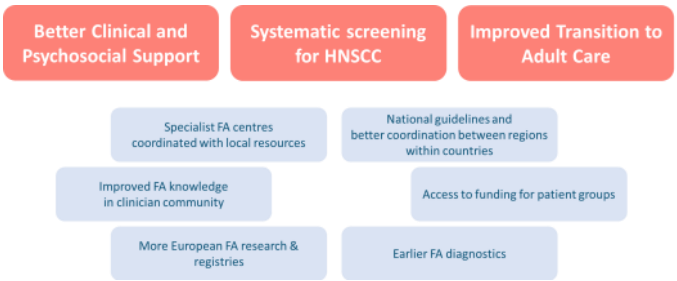
A small group of medical professionals and support group representatives met in Utrecht in Jan 2019 to prepare for a Start-up Meeting in March 2020.

Utrecht Planning Meeting

Due to COVID-19, this March meeting had to be delayed and changed into a virtual Zoom meeting on 4th Sept. This was attended by over 40 medical professionals, researchers, patients support group representatives and patients from 10 European countries, discussed proposals for the priorities, the objectives and the form of the organisation.

It was agreed that the vision for the organisation should be **to achieve equal access to optimised care for people across Europe affected by Fanconi Anaemia** and that it would do this **by connecting FA patients, doctors and scientists across Europe and acting as a facilitator for education and communication, fundraising, research collaboration and sharing of best practices and infrastructure**.

Through discussion at this meeting, combined with earlier meetings and surveys, the priority areas for FA Europe were discussed, and an attempt made to encompass them all in one single diagram, as shown here.



Priorities Identified for FA Europe

Currently, we are in the process of formalising the organisation by registering it in the Netherlands, preparing for a Europe-wide meeting of ENT specialist on cancer management for FA patients, and preparing a letter for each country to give to relevant medical professionals about the importance of HPV vaccinations for all people with FA.

Our Fanconi Hope consultant and researcher Trustees, Dr Stefan Meyer, Prof Marc Tischkowitz, Prof Josu de la Fuente and Dr Nigel Jones, have all been supporting the FA Europe initiative, and we are very grateful to have their expertise involved.

Marc Tischkowitz has made a particular contribution to representing the UK's interests in European involvement which is threatened by Brexit, by coordinating a letter to the Government via the Lancet, which warns of the impact on people with rare diseases if we are no longer allowed to be part of the European Reference Networks. These networks enable knowledge and expertise to be shared widely across Europe. This is particularly important in the case of rare diseases where no one country may have enough patients for new drug trials to be viable for example.

Key figures in Europe involved in setting up FA Europe are Professor Hanneke Takkenberg, who runs the Netherlands FA Patient Support Group and Greta Bertolucci, who is Italian, lives in Spain and also speaks English and French - so a great asset to the organisation!

Prof Hanneke Takkenberg

Greta Bertolucci

Dutch Consultants Prof Remco de Bree, Prof Ruud Brakenhoff and Dr Marc Bierings, and Spanish researcher Dr Juan Bueren are also supporting the formation of the organisation and helping us to carry out some of the initial actions.

Countries Currently Involved in FA Europe

Proton Therapy Research Grant Awarded

Fanconi Hope has awarded a grant of £92,000 to the University of Manchester for a 3 year investigation into the optimised use of Proton Beam Therapy for the treatment of cancer in FA patients. A massive 'Thank You' is due to our FA families, relatives and friends whose fundraising efforts over the last 2 years have made this project possible!

This study uses the new state-of-the-art Proton Therapy facility in the UK at The Christie NHS Foundation Trust in Manchester and an outstanding team of investigators is being assembled. The study represents exceptional value for money for Fanconi Hope and there is real potential for rapid translation into the clinical environment.

The Duchess of Devonshire

We were delighted to receive this message from our Patron, the Duchess of Devonshire DL:-

"As Patron of the Fanconi Hope Charitable Trust I have always believed that this small charity could have a big impact on many lives. The project to be undertaken at the impressive new Proton Therapy facilities at the University of Manchester indeed holds great promise to extend the lives of many of those affected by Fanconi Anaemia. The community that Fanconi Hope serves has responded magnificently by uniting behind the call to raise funds for this vital project and together with the passion and drive of the Trustees I have no doubt that this small charity and its supporters will continue to make a difference for all those suffering because of Fanconi Anaemia".

UK FA Registry Update from Beth Lee

Beth Lee

I started working as Research and Family Liaison Coordinator for Fanconi Hope in May 2016 . It has been an amazing four years and I enjoy this role so much!

Over the years I have spoken to many families and been able to give much needed specialist advice and support. I have had many valuable discussions with people at diagnosis and at other complicated and difficult times. People often ask me to explain what treatments and tests to expect and what surveillance is required in adulthood. Occasionally I deal with queries from consultants who have little experience in dealing with FA.

As well as my role of supporting families I manage the Registry "an observational study into the long term health effects of Fanconi Anaemia". This is going really well and I would like to thank everyone who has joined in. We now have 55 people signed up which is wonderful, however we would like everyone to be involved. So if you would like to be added please send me an email at beth.lee@fanconihope.org and I will send you the information you need for your consideration.

The aim of the study is to find out the problems affecting people with FA, and discover the best ways of managing them so that we can provide better and more appropriate care in the future.

I would urge anyone who hasn't had a chance to talk with me yet to contact as I would love to speak with all of you. So please feel free to email or leave a message on my mobile and we can arrange a call.

Wishing you all a Happy Holiday and a Peaceful New Year , Beth

beth.lee@fanconihope.org Mob 07391 782115

Your Help is Needed for Stacey's Doctoral Thesis

RESEARCH INVITE

I am working on research to understand what it is like for individuals and families living with Fanconi Anemia and Diamond-Blackfan Anemia.
I am interested in understanding:

- Your experience
- The challenges you face
- The supports and resources you draw on
- How better to support individuals and families

If you are interested in speaking with me, please get in touch:
Stacey Barkley
U1826607@uel.ac.uk

Stacey Barkley would love to hear from you if you are-

- A family member of someone with FA, based in the UK
- A person with FA aged over 18 based in the UK.

The research will be asking directly about your experiences of diagnosis and your journey beyond that and the support that has been available to you.

Please do get in touch with Stacey for further information at U1826607@uel.ac.uk. Absolutely no obligation to take part.

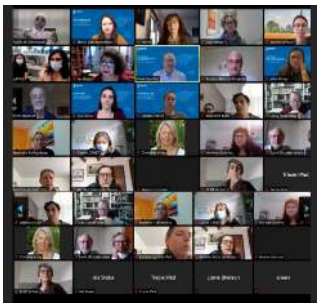
Stacey Barkley

Fanconi Hope has been working with its sister Charity DBA UK (for Diamond Blackfan Anaemia) and Paula Corredor Lopez, a Clinical Psychologist at the University of East London (and an FA parent) to initiate some research onto the psychological effects of FA and DBA. This is a field in which there has been very little research to date so we are very keen that this work is supported by you, our UK FA families.

At the University of East London School of Psychology they are trying to build up the research evidence base around better understanding the psychological needs of those with FA and their families.
Stacey Barkley is their first Clinical Psychologist in training conducting her Doctoral thesis on FA.

International Update - Focus on Cancer

The US-based Fanconi Anemia Research Fund continues to develop its international support aspirations. One such initiative is the global FA summit meeting held on Zoom last October, in which Fanconi Hope took part along with many other countries around the world. This was an opportunity for countries to highlight the issues most concerning them in relation to FA care in their countries. It was clear listening to the attendees that access to and funding for treatments, and medical awareness of FA varies widely from country to country and there is much work to do to equalise care provision and support. This is something that FARF is determined to help with globally and FA Europe aspires to do within Europe.



3rd Annual Global FA Summit Meeting

FARF now spends around $2M annually on research, mostly cancer-related. A key focus is on Head and Neck and Anogenital cancers, given how common they are in our FA community, so there are a number of initiatives either under way or planned for 2021;

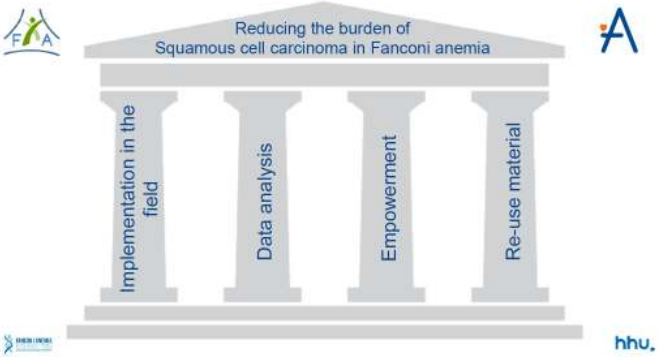
- They will be collaborating with the organisation Stand up To Cancer and three other HNSCC non-profit organizations in the US, to fund a Research Team looking in particular for new ideas from people who don't have FA expertise. This will unlock considerable extra funding for FA cancer research, which is great news.
- FARF are establishing a Head and Neck Cancer Consortium (which includes anogenital cancers), and which is expected to have global representation.
- FARF have set up a Virtual Tumour Board, consisting of 8 clinicians with wide expertise who meet to discuss difficult cases. Currently operating within the US, they are working to include international patients as well, although accessing international medical records is a challenging issue.
- FARF hold annual Joel Walker Head and Neck Cancer Meetings. These meetings bring a range of key experts together and help to drive research into Squamous Cell Carcinoma early detection and treatment.

Image courtesy of FARF

In Germany, Dr Eunike Velleuer and her team have been spearheading the development of an early cancer detection technique under a research project called 'Reducing the burden of Squamous Cell Carcinoma in Fanconi Anemia'. Earlier this year they published their long-awaited paper on the outcome of many years of oral brush sampling of FA patients to see if the technique would result in the early identification of mouth cancers.

The results did indeed show that they correctly diagnosed cancer in FA patients 100% of the time. Amazingly, 63% of worrisome lesions were identified as pre-cancer or stage 1 cancer, enabling successful surgical removal. The team, financially supported by FARF, are now working on educating specialists in other countries in the use of their technique, and we will be supporting these efforts through FA Europe.

Under a new grant from FARF, the team are working on 4 'pillars' as shown in the diagram below.



For building up the Patients' Empowerment pillar their goals are:

- Producing training videos of mouth self-inspection (with brochures later),
- Developing Guidelines/Recommendations for self-inspection,
- Practical training and practice units are provided at FA meetings and home visits,
- A first version of an App for self-documentation and progress monitoring.

FA Europe will be helping to raise awareness of this technique amongst the Ear Nose and Throat (ENT) community across Europe.

Joint UK - Netherlands FA Adults Meeting Sept 2021 – Put your name down now!

Fanconi Hope, in conjunction with our Netherlands counterpart FA support organisation, are sponsoring an FA Adults weekend from Fri 3rd - Mon 6th Sept, 2021 in Efteling Park in the Netherlands. (https://www.efteling.com/en) (Assuming that it is safe to travel by that date).

The event, arranged by and run by FA adults, is an opportunity for FA Adults age 18 and over from our two countries to enjoy a weekend of relaxation/excitement/enjoyment/socialising in this very traditional theme park. A visit is seen as a 'must' for everyone in the Netherlands!

Accommodation for a total of 18 people is being provided on-site in 2 lodges. Beth Lee will be on hand to talk about FA issues if required, but primarily this weekend is a chance to get away from it all and have a good time.

Efteling is an old-world theme park in the Netherlands. In their words: "Looking for exciting rollercoasters, enchanting attractions or spectacular park shows? Everyone will find what they are looking for in Efteling. Discover the largest theme park in The Netherlands. A unique park in the middle of nature".

Fanconi Hope will pay for travel, accommodation, breakfasts and evening meals for each participating FA Adult. 9 places are available to UK FA adults.

If you are interested in attending, please register your interest with Beth Lee at beth.lee@fanconihope.org.

Fundraising in 2020

Our year started well however, with the donation of £1750 from Stacey and Jake Perry's fundraiser at the end of last year. In Stacey's words; "The event featured live music acts and various stalls, a tombola and raffle to raise money and awareness for Fanconi Hope. We had a lot of support from our home town and we were really pleased with the amount raised. It was a great day and the event went really well".

Also in January came the cheque for almost £10,000 from students at Presdales School in Hertfordshire who had selected Fanconi Hope as their Charity of the Year in 2019 in memory of one of their fellow students, Sabrina Foufa, who had FA and sadly passed away earlier in the year.

We were grateful during the summer to receive a substantial cheque from Kevin Smith following the untimely death of his wife Joanne. Joanne wished this gift to be made to Fanconi Hope to help others in a similar position to hers. In discussion with Kevin, we have agreed that this money be used to support future FA Adult meetings in her memory.

In the Autumn we were delighted to reach our target of £100,000 to fund the Proton Beam Therapy Research Project

Thank you to all the amazing families and individuals who have found time, energy and the enthusiasm to continue their fundraising efforts we all need to pull together to raise funds to ensure family support, events and vital research can continue in future years.

Fundraising and How You Can Get Involved

Whilst organised Fun Runs, Half Marathons etc might still not be possible for some time, you can organise a personal virtual event . (See https://runforcharity.com/fanconi-hope/virtual-running-events).

- Just choose your event and sign up
- Complete your run
- Upload your evidence to Virtual@runforcharity.com on completion
- Put your feet up
- Wait for the postman to drop off your medal!

We do also have some places left for some of the genuine runs in 2021, including the Great North and South Runs and the Great Manchester 10K, should they be able to go ahead. Please contact us at info@fanconihope.org if you are interested in places and we will put your names down on the list. For those of you who paid to run this year, your places will be made available again to you in 2021.

And for a number of other real events, once they are allowed, you can choose to raise money for Fanconi Hope from a large number of varied events throughout the year. For more details see https://runforcharity.com/charity/fanconi-hope).

To raise money while you spend, without costing you a penny please consider using EasyFundraising and Amazon Smile.

Why Your Fundraising is important to us

Increasingly we are seeing the benefits of working with European and international partners to:

- Ensure maximum knowledge sharing,
- Access the best research expertise,
- Make best use of limited resources,
- Enable multi-country trials and,
- Ensure maximum coordination of activities between the various FA groups/specialists/researchers worldwide .

From our own experience with the International FA Gene Therapy Working Group, which ran for 9 years from 2010, we saw the incredible value of getting experts together in the same room both formally and informally to share knowledge and ideas. Only in these situations were they be able to share unpublished data from their research and trials activities. This undoubtedly led to the accelerated development of Gene Therapy trials for FA, which are now underway in a coordinated fashion in the US, the UK and Europe.

In future we want our UK consultants and researchers to participate more actively in FA specialist groups both within Europe and the US but **meetings cost money!** Whilst meetings on Zoom are certainly at minimal cost, we do want to engage in face-to-face meetings wherever possible. Please help us achieve our aims in improving the lives of people with FA by raising money to allow our experts to be working at the cutting edge of research, armed with the knowledge of the best current treatment options available around the world.

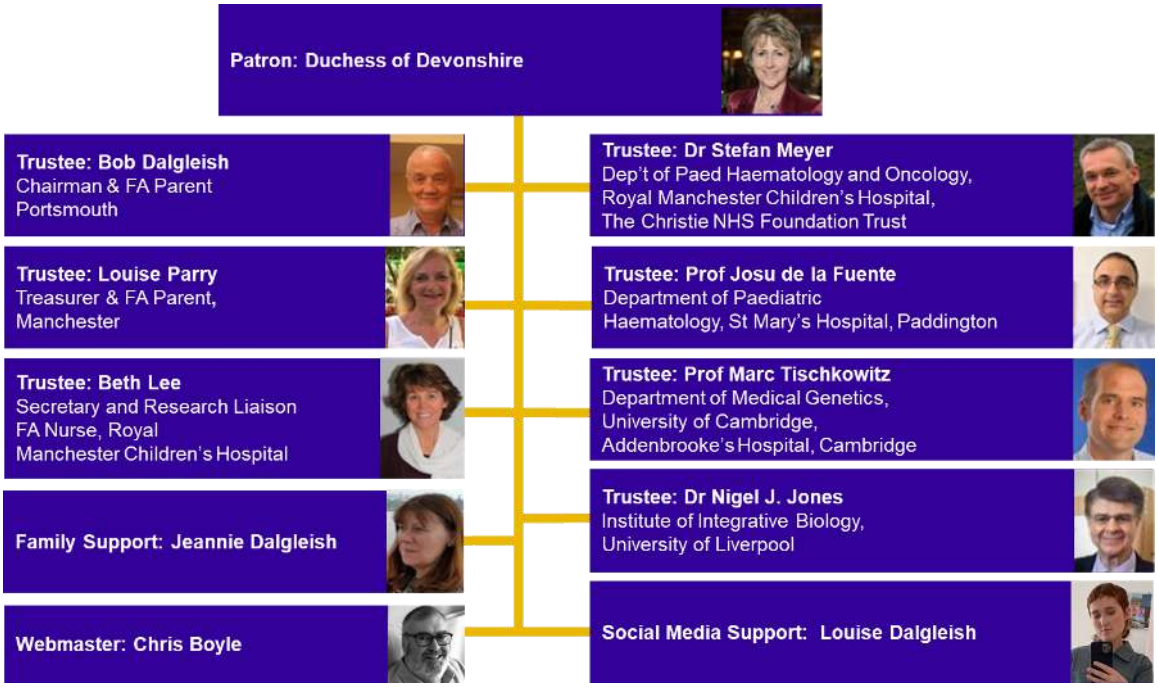
Fanconi Hope Team News

Congratulations are due to two of our trustees who have been promoted to Professor status this year.
Josu de la Fuente became Professor of Practice (Cellular and Gene Therapy) at Imperial College London in September 2020.

Marc Tischkowitz became Professor of Medical Genetics, at the University of Cambridge in December 2020.

Chris Boyle joined us in early summer as a volunteer webmaster, providing many hours of expert assistance in upgrading our website and helping to set up a sister site www.faeurope.org. Many thanks are due to Chris for his willing and enthusiastic support.

We were delighted to have volunteer support this summer from intern Shannon Lee-Roebuck from Keele University. The internship was created to help us develop their social media presence and improve the posts on our website, focusing on targeting a younger demographic. Her psychology background has also given us an insight into how those with disabilities such as dyslexia and dyspraxia view our website. During the internship she also learnt how to use Photoshop which resulted in producing graphics to promote our online webinars.



Our Current Organisation

Daniel Ayling Fanconi Anaemia Charity closes and transfers funds to Fanconi Hope

We were recently contacted by Kim Ayling, the mother of a son, Daniel, who sadly passed away shortly after being born in 2005, to say that they wished to transfer the balance of their charity funds, around £3,000, to Fanconi Hope to help fund research. Daniel's parents started the Daniel Ayling Fanconi Anaemia Charity in his memory, as they wanted his name to live on and the only way they could do that was by raising awareness of the condition and raising money to pay for research. Over the years, quiz nights, endless boot sales and London marathon entries allowed the Charity to fund work by Professor Chris Mathew at Guy's Hospital. The first piece of equipment they funded was a centrifuge which had Daniel's name on it, so his name lives on!

After 5 years they have decided to stop fund raising, but are grateful to know that the last money has gone to Fanconi Hope, because they see that our Charity is doing what they wanted to promote awareness and fund research. Kim passes on the message, on behalf of all Daniel's family, that they wish us every success with our continuing charity work, and we in turn are very grateful for this substantial donation, which will be ringfenced for research purposes.

Support Available

New Genetic Disorders UK Helpline

Did you know that GD UK now have a genetic counsellor-led helpline? This service is for people with a genetic disorder, their relatives, professionals and anyone who needs to know more about genetic disorders and how to cope with the difficulties they can present. It is a confidential and non-judgemental space for you to find out the information you need and discuss your feelings, concerns and fears about a genetic disorder.

You can leave a voicemail or send an email at any time and they will aim to respond within three working days. Your enquiry will be treated in the strictest confidence. You can call free on 0800 987 8985,

Email: helpline@geneticdisordersuk.org or use their Contact form: http://www.geneticdisordersuk.org/contact-us/

FA Information for your medical team

If you meet doctors and nurses who know little about FA we have produced this short document for you to show them. so this is useful document to show them.

You can download it at https://fanconihope.org/wp-content/uploads/2019/08/About-Fanconi-Anaemia-for-Non-FA-specialist-Medical-Professionals.pdf or use the QR code shown. The information Sheet is aimed at medical professionals who are not FA specialists and is brief enough that they might take the time to read it!

Information Sheets for Dentists and ENT Specialists

Don't forget we also have information Sheets specifically for you to give to your Dentist and ENT specialists to help them understand the importance of checking for Head and Neck Cancers. These were produced by FARF and have been tailored by Fanconi Hope for the UK.

For Dentists

https://fanconihope.org/wp-content/uploads/2019/03/2018-SCC-for-Dentists-ENGLISH-UK.pdf

For ENT Specialists

https://fanconihope.org/wp-content/uploads/2019/03/2018-SCC-for-ENTs-ENGLISH-UK.pdf

FA Teens and Adults—Unsure about Long Term Screening and Surveillance recommendations?

If you are unsure about Long term Screening and Surveillance recommendations, then get the App! You can download it at https://livingwithfa.glideapp.io or use this QR code, and save it to your home screen.

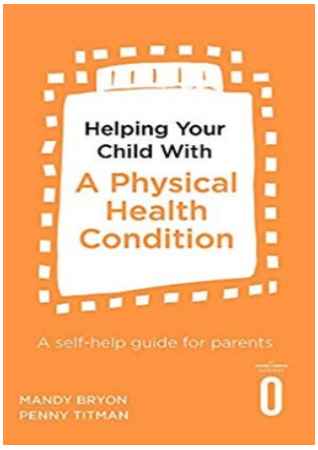
Screening and surveillance regimes will not be the same for everyone, but this guide should inform your discussions with your FA consultant.

Have you received your free copy of **Helping Your Child with a Physical Health Condition: A self-help guide for parents?** If you would like a free copy please contact Beth Lee at beth.lee@fanconihope.org and she will send you one.

This book, written by Clinical Psychologists at Great Ormond Street Hospital, can help you with:

- Emotional support for managing difference and dealing with difficult behaviour
- Practical suggestions for easing hospital anxiety or navigating feeding problems
- Advice on what to say and when to your child about their illness
- How to ensure you don't neglect yourself or the rest of your family

Written by experts in childhood illness, this step-by-step guide is for any parent who feels isolated or lacking in support.



The Together for Healthy Marrow Alliance

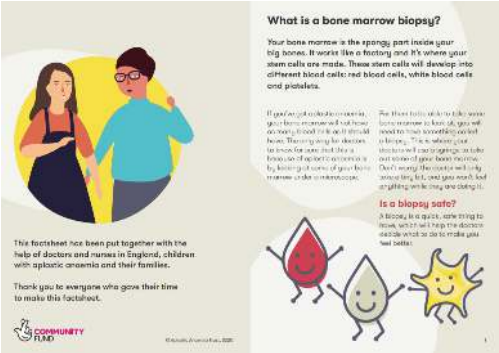
We formed this alliance last year in partnership with For other charities dealing with inherited bone marrow failure conditions, the Aplastic Anaemia Trust (AAT), DBA UK, DC Action and PNH UK. The idea for this Alliance was sparked by a discussion initiated by Jeannie Dalgleish with a view to making the best use of resources to tackle common problems between similar medical conditions.

Through this alliance we were made aware that the AAT was developing a series of booklets for young people on a range of topics around bone marrow failure. These were published in Nov 20.

For example, they have a booklet about bone marrow biopsies aimed at 5-11 year olds. You can see the full range of booklets here: https://www.theaat.org.uk/marrowkidz

Fanconi Hope Social Media

- Fanconi Hope Page
- Fanconi Hope Family Support Group
- fanconi_hope
- fanconihope



And don't forget FARF Resources!

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

FARF have an amazing amount of resources available. Their new 5th edition FA Clinical Guidelines document is due out very shortly, and Guidance for families will be increasingly appearing on their website. We don't want to duplicate effort, so please make sure you sign up to their Newsletters and Facebook group. Hopefully next year should see the return of Camp Sunshine and their FA Adults meeting, both of which are open to UK and Irish families. www.fanconi.org.

A sad farewell to Joanne Smith

In April 2020 we had to say goodbye to Joanne Smith, after a medical battle too far. She was always such a beacon of hope for others with FA, surviving to the age of 54. Many of you will have met Joanne over the years as she attended many FA events both here and in the US. Joanne, despite her numerous health issues, was always cheerful and an example to us all in managing to deal with adversity. She was a keen supporter of Fanconi Hope, and is shown in the picture here in a sponsored park run with her husband Kevin.

Kevin has done a wonderful job in caring for Joanne over all the years, and we look forwards to his continued involvement with Fanconi Hope events in the future, as he has indicated that he wishes to do.

Joanne's memory will however live on as she bequeathed a significant sum of money which Kevin has agreed should be called the Joanne Smith Memorial Fund to help pay for future FA Adult meetings.

One Family's Story - David & Sian Jones and sons Finley and Zach

A BIT ABOUT US

My partner David and I have two wonderful Sons; Finley (aged 10) and Zach (aged 6) and we live in Wrexham, North Wales.

When both of our Sons were born, they failed their new-born hearing test at just a few days old in hospital. They both have a hearing loss and wear hearing aids, which work wonderfully for them. This was one of the reasons that the fantastic Dr Webber at Wrexham Maelor suggested we had some Genetic testing to look in to why both boys had a hearing loss and to see if it was part of a syndrome. They decided to do the tests on our youngest Son Zach as he had some additional concerns – such as kidney abnormalities, some café au lait marks and short stature - generally, Zach clothes size is 3 years younger than his age.

THE TESTS /RESULTS

Genetic tests such as these take months, 9 months in fact - as they were not looking for anything specifically so just tested for absolutely everything. We weren't worried at the time of the tests, we were just happy that investigations were taking place and hoped they would find something that may help the boys hearing.

In April 2018, we had a phone call asking for us to come into the Genetic department in a couple of days time. I remember feeling really positive going into the room, thinking we'd have some closure, that everything would be okay and that our minds would be put at ease. Our hearts broke that day. When the Genetic Doctor said the words Fanconi Anaemia we'd never heard of it – you hear the word anaemia and I just assumed he was a bit low on iron.

The Doctor explained how it was a very serious and life-changing condition and that it was very rare. I remember noticing the tissues on the table in the Genetics room where we were sat, I really didn't expect to be needing them.

When we left the hospital that day, Dave and I felt like our world had ended. We both picked the boys up from School and just spent the evening loving them, playing with them, hugging them and just trying to paint a smile on our faces until the boys went to bed. Obviously we've always been very grateful to have our two amazing Sons whom we love very much, but hearing such devastating news, we wanted to be with them every single minute.

SINCE ZACH's DIAGNOSIS

Due to the complexities of the condition it took a further 4 months for Zach's diagnosis to be confirmed – that was a horrific time for us – you can't grieve as he may not have it – it was so unsettling. We spent all of our spare time researching into the condition as much as we could, but there's not much information out there and the medical teams in Wrexham didn't really have any knowledge or experience of the condition. It was really hard but we kept strong in front of the boys.

I cannot praise the NHS enough, FA is very complex and affects every cell in the body and the organs, so when Zach was diagnosed he had lots of hospital appointments and a whole load of tests to check his current condition. We feel extremely grateful and lucky to have been put in touch with the fantastic team based in the Royal Manchester Children's Hospital and it felt like such a huge relief to be able to talk to someone who had heard about FA, never mind someone who actually specialised in the condition! They have been amazing.

Knowing that Zach would need a bone marrow transplant in the future, we were advised that the best possible match for Zach would be a sibling; our hopes were on Finley being a match. Long story short, several tests later and 8 months after Zach's diagnosis; big brother Finley was diagnosed with FA too.

Words just can't describe how that felt. Both of our beautiful boys being diagnosed with this. We were just broken.

Taking the positives from all that we could, we do appreciate how lucky we are that we even had these tests done – generally Children find out that they have FA as they have Leukaemia or go into bone marrow failure. We have advanced notice and now the boys have regular blood tests as well as annual bone marrow biopsies/aspirations to keep a check on how they are doing. We are eternally grateful to be in Stefan Meyer and Beth Lee's fantastic care at Manchester hospital. Stefan and Beth are truly wonderful and we don't know what we would do without them!

WHAT DO THE BOYS KNOW?

Up until recently, the boys have had no awareness of their condition. We wanted to come to terms with it ourselves and saw no need to rush-in telling them.

I recently overheard Finley comforting Zach who was worried about having another blood test, I went into Fin's bedroom and very organically explained to the boys that they have red and white soldiers in their body and that one day their Soldiers will become too tired, so we'll need to put some new soldiers inside their bodies (Bone Marrow Transplant); I explained that not everyone needed to have new soldiers and that's why we have so many trips to hospital. The boys are little superstars and we try to make each hospital trip an adventure and something they look forward to – they take turns in deciding where we can go for lunch and even when they've had MRI scans and their Bone Marrow op's they come away with lovely memories of the day. Finley still talks about the best sleep he's ever had after his last bone marrow aspiration.

Finally, we'd like to say a massive thanks to Fanconi Hope, the work you guys do is amazing and has provided us with much comfort, knowledge and support. I have such fabulous memories of the Fanconi Hope conference last year, where I came away with so much more knowledge and met some lovely families. Now that the boys are aware of their condition, we're looking forward to the next conference where we will all attend as a family!

Lots of love and best wishes to you all

Sian and David

More UK FA Family Pictures

Here are a selection of the photos you sent in following a call for photos to help with publicity and fundraising.

Erring on the side of caution, we have not named individuals.

The Perrys

The Millers

The Hamlins

The Gudhkas

The Jones Family