friends Together

Vol 5, Issue 2 Jul 2022

FOP Friends exists to **help find a treatment and a cure** for the rare genetic condition fibrodysplasia ossificans progressiva (FOP), and to **support the families** affected by it

What a Weekend!

This May saw the return of our Conference and Family Gathering – and what an event it was!

We were thrilled and humbled to welcome families, medical specialists and speakers from around the world to Manchester, England, for our 4th Conference. The event also was a celebration of our 10th birthday as a registered charity.

The three-day event began with an informal family evening which gave our families the opportunity to meet up after – the smiles on their faces showed just how much they had missed being around others who understand. Saturday was opened with a special video message from the always-fabulous Stephen Fry. This was followed by a full day of presentations and workshops with FOP specialists.

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Inside

A word from Nicky

With the warmer weather here, we were excited to have been the chosen charity for the Windlesham Picnic. It's a picnic- but for grown-ups! The event attracted over 350 guests and was a fabulous event. The theme this year was '100 years of the BBC' so my husband and I went dressed as Worzel Gummidge and Aunt Sally

The FOP Friends Conference back in May did not fail to disappoint. It was my third conference and each time, I learn so much to help my daughter Isla, and get invaluable time with other FOPers and their families. I particularly enjoyed meeting the doctors and dentists from around the world and the fabulous Hope and Karen from the IFOPA who had travelled from Kansas to share the super useful Ability Toolbox.

A little project I have been working on is creating a set of inspirational quotes from the FOP community. Isla's chosen one is a good reminder to us all – "Focus on what you can do. Not what you can't." We hope you enjoy reading them, and if you have one, do get in touch.

Nicky, FOP Friends Trustee

Behind the Scenes

Chris has been continuing the preparations for the drug approval process for NICE (National Institute for Health and Care Excellence, UK's process for approving new drugs for access on the NHS).

We have also begun to work with Reaslise Advocacy to learn more about the HST (Highly Specialised Technologies) process, again with a view to getting any potential treatments for FOP approved for access on the NHS.We will shortly be inviting members of our FOP community and their carers to complete a survey to ensure their voice is heard in this process.

Chris took part in the Genomics England 100,000 Genomes Project which ran over two days. This involved attending workshops along with other patient organisations to input on inclusion criteria for the new-born whole genome screen programme. He also took part in the Beacon for Rare Diseases Patient Advisory group, inputting into their future programmes to support rare disease organisations. There was also an IFOPA Board meeting where they discussed future plans for their programming, he also chaired the first IPC meeting for the year where they talked about plans for the international community. A STOPFOP funding meeting was also held, to discuss the trial and its progress.

Helen was able to raise awareness of FOP with radiology students at the University of Canterbury. She was able to highlight key things to look out for on scans such as the toes and enchondromas on the knee joints. Perhaps more importantly, she was able to give a patient carer's perspective on living with FOP and what medical students need to know when providing care services for those with a rare condition

Chris also worked with Steve Middleton, a script writer, as we develop new and updated content for awareness, diagnosis and care videos. We look forward to bringing you further updates on these projects in the autumn. For more information about the UK's drug approval process, please visit: **www.fopfriends.com**

Outstanding Oliver

Oliver proved he is following in his father's footsteps when they both attended an event at Ipsen, for Global FOP Awareness Day.

Oliver, Chris and Luchian travelled to Ipsen's UK Head Office in Slough, to give presentations to employees about the impact of living with FOP. Oliver talked about how FOP has affected him growing up, and his hopes and dreams for the future. Luciana also spoke about growing up with a rare disease and about study and careers.

There was an audience of around 100 people, and the event was also live streamed to other employees who were working from home. It was an emotional seminar for the colleagues listening, who found Oliver and Luciana's stories inspiring. Oliver impressed everyone with his confidence – especially since he is so young. Their words had a truly motivating impact on those who are working to find an effective treatment for FOP many colleagues said it gave a real meaning to their work. Thank you to Oliver and Luciana for sharing your stories.

Queen's Jubilee Honours List for Helen

Helen, one of our trustees and mum to Oliver age 14 who lives with FOP, was honoured and amazed to have received a British Empire Medal in the Queen's Jubilee Honours list in June. The award was given in recognition for Helen's services to people living with fibrodysplasia ossificans progressiva and their families.

"It was a complete surprise when the letter arrived in the post. I didn't even know I had been nominated!" says Helen, who is also mum to Leo, 12, and Harry, 9. Helen has been tirelessly working to raise money, funds and awareness for FOP since Oliver's diagnosis when he was just 13 months old. "We never set out to run a charity on this scale and with this importance, it's just evolved over the years," reflects Helen, "but thanks to the support from our friends and family, and the support of everyone else who is affected by FOP, we have become this nationally and internationally recognised charity. We're definitely punching above our weight!".

Helen was sworn to secrecy about the award, so had to keep it to just a few people before the announcement. "We went out for dinner the night before the list was published and told the boys and my niece and nephew, Elise and Eddie. Elise was just so thrilled for me! She couldn't contain her excitement! It was just lovely!"

If you're looking for Helen at FOP Friends, you usually have to peek behind the scenes to find her! Helen runs the office - from posting letters to writing books and reports to project management. She speaks to people from all walks of life and has been known to make a nuisance of herself (once or twice!) when people are looking for answers! Helen also advocates for the families when they need that extra bit of support and need to know that they are not alone.

Helen will receive her BEM later this year at a ceremony in Manchester, where the medal will be presented by the Lord Lieutenant of Manchester. She will then be invited to one of the Queen's Garden Parties at Buckingham Palace next year.

Helen hopes that her award will help to raise further awareness of the charity and of FOP, and that it will give FOP Friends an even louder voice as it continues its work to support everyone affected by FOP.

"It is a real honour for my work for FOP Friends to have been recognised but was wholly unexpected. Growing up, I always assumed I would be a teacher – a job I love to this day – but life had other plans for me. I have met the most wonderful people over the past ten years and my life is richer because of them. I just hope that one day, FOP won't be the diagnosis it is today, and that everyone living with FOP can lead a life free of pain, and of their own choosing".

Alma's Book Award

June saw our children with FOP receive a second beautiful book, in memory of Alma Triffitt.

Jim, Alma's husband, wanted to gift all the children and young people a new book in recognition of the challenges they live with on a daily basis. Thanks to the amazing team at Blackwell's in Oxford, led by David, the children and young people received the most beautiful and varied selection of books – they perfectly reflect the characters of our amazing young people. Take a look at a few of them…we're sure Alma would have loved the books too.

What a Weekend – continued…

While we may have had a few hiccups along the way…we got there in the end – and in style!

We had attendees from England, Scotland, America, Brazil, Canada, Greece, Ireland, Netherlands, Poland, and (virtually) South Africa. It truly was an international affair! We welcomed babies, children, young people and adults living with FOP and POH.

Our Friday night drinks gathering was packed out, with families having four years of news to catch up. The kids were beyond excited to see each other -there were squeals everywhere! There were also families who were meeting in real life for the very first time! Many people felt like they were meeting long lost friends, yet had never even met in person. It was such a special and emotional evening.

This year, we were able to offer our families a dental consultation as well as the usual clinical appointment. Professor Keen and Dr Bubbear led the clinical appointments. It was also the first opportunity many of our families had met Martyn Dudley, the FOP clinical nurse specialist from RNOH. Our families were particularly excited to have the opportunity for a dental consultation with FOP specialists. Ms Gehan Abou-Ameira and Clive Friedman met with our families, accompanied by Ms Jessie Tebbutt, who is the Chief Dental Officer´s Clinical Fellow for Health England. Ms Tebbutt is interested in learning more about dental care for both FOP and POH patients, as well as for rare diseases in a wider context.

We had our presentations from FOP specialists from around the world, including Mona Al Mukkadam MD and Patricia Delai MD. Professor Fred Kaplan, Professor Bob Pignolo and Dr Chris Scott, all joined us by videolink.

The StopFOP team, led by Dr. Bernard Smilde gave us an update from the trial site in Amsterdam, while Dr Ellie Williams brought along her Genetics Escape Room challenge for delegates to have a go!

Pharmaceutical companies were also there to bring updates to the community about their progress to date, giving us all hope.

Perhaps the unsung heroes of the weekend were the wonderful volunteers who ran the FriendZone, led by Fiona White and Janet Plumb. No-one passing through the FriendZone would have had any idea what mighty challenges these young people were fighting if they heard the laughter and saw the smiles on their faces. The FriendZone provides a safe space for parents to leave their children in expert hands, confident that they will have the best time! The children have the chance to hang out, play, create, chat and snack! Without these volunteers, we simply wouldn't be able to deliver the invaluable programme that we do for the adults. We would be lost without you!

The children and young people who attended the conference were lucky enough this year to have been gifted a special goody bag from an anonymous friend! They all received a hand-picked gift – from Lego and books, to haircare products and Pokemon – along with seeds, and chocolate treats. There were smiles aplenty!

In addition to their gift bags, the children were also fortunate enough to have been given another treat from a second anonymous donor- a butterfly kit! We are enjoying seeing the photos of the butterflies as they grow and fly free.

We were thrilled to welcome Hope Newport and Karen Kirchoff from the IFOPA to England, to meet the families they have known and supported virtually for many years. They also brought with them gizmos and gadgets from the Ability Tool box to help those living with FOP and POH maintain their independence and dignity.

We had an emotional Sunday morning, as we held the UK's first screening of the Tin Soldiers film. Dr Patricia Delai was present to introduce the film, and to take questions afterwards.

The trustees are still on cloud nine as they reflect on the overwhelming success of the weekend – we had been apprehensive we wouldn't be able to deliver an event as good as in previous years. We knew that recent and current events would make holding an in-person conference an even bigger challenge, but thanks to the enthusiasm and positivity everyone brought to the weekend, it was even better than we could have hoped for. The trustees would like to thank each and every person who came along to the weekend and poured their heart and soul into the event. We saw that we have hope. We showed that we truly are, stronger together. For more photos of the weekend, visit: **www.fopfriends.com/conference-and-family-gathering-2022**

We would like to thank the sponsors of event, without whom, our conference would not have been possible.

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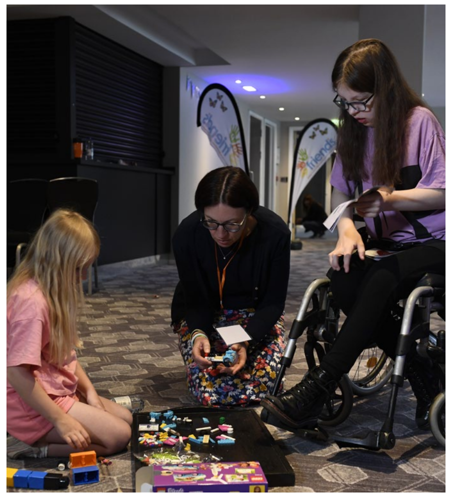
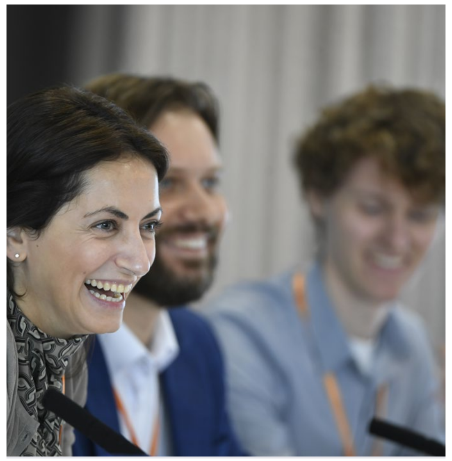


> FOP does not affect your spirit, FOP does not affect your mind. Remember that F U N is as important as F O P. Live your life with dignity and spirit. Stay connected with others… stay connected with other families… They will give you great advice and great comfort on this journey.
>
> **Wise words from Professor Kaplan, from his virtual presentation.**



Friendships Matter

Sharon Kantanie is one of our FOP friends and lives in Tennessee, USA.

She lives with FOP and has been a source of friendship and support for so many, the world over. She has a passion for all things creative and loves to papercraft and share her skills with others. Sharon was the editor of the 'What is FOP? A Guidebook for Families', which continues to be an invaluable resource for every family. Her wise words provide comfort and guidance to those who need it. Sharon writes a blog, and she has kindly allowed us to share her thoughts on friendships here:

Having a rare and progressive disability and being a natural introvert haven't made it easy to develop friendships. Fortunately, I have been able to develop a few close friendships in my lifetime that have made life much better. Unfortunately, in almost all of those cases, the friendships have been mostly long distance.

First there was the friend I made when my first hip joint turned to bone in middle school. She was the lifeline I needed: distracting me from pain, carrying my books at school, and being my lunch buddy (Lunch is undoubtedly the worst time of day when you feel different, and yearbook day is like a million lunches.). A year later my family moved and, though she and I remained close friends, I no longer had anyone by my side on a daily basis that wasn't part of my family. Later came the friend I made when she was trying to help a patient with the same rare disease that I have. Did I mention that she is a doctor in Brazil, which is no where near Tennessee? Much of our friendship developed online, though now we try to get together in person at least once a year. That hasn't happened since 2019 because of Covid, but it hasn't stopped us from dreaming and hoping.

I try to justify the fact that I don't have a lot of friends by saying that dealing with my disability is a lot of trouble. Well, that is partly true. Nothing about fibrodysplasia ossificans progressiva (FOP), a disease that causes bone to form in muscles, joints, and other connective tissue, progressively and significantly restricting movement, is easy. At the same time, I believe I have a lot to offer as a friend, mostly because I can now see myself through the eyes of the few friends I have. I am very grateful for that.

Writing on the subject of friendship when you have a disability came foremost to my mind recently for two reasons. Recently I read a social media post written by a mom who wanted to find summer plans for her son who shares my same disability and was very disappointed and frustrated at the lack of options. Many other mothers responded with similar concerns. One mother, whose daughter is now an adult, wrote about those particularly hard years of adolescence, saying, "I lost faith and trust in so much, but never in my daughter." It reminded me of lonelier times before I learned to keep myself entertained and stopped worrying that so much of the world and the people in it felt closed off to me.

Then I read another post from a mom whose 8-year-old daughter was starting to feel different from her peers. The saddest part is that Isla, this young girl, is my hero. She does things you might never think she could do with her level of disability: riding and caring for horses, dancing and gymnastics, and living her best life. Her dream is to open a happiness store.

So, if you are reading this, I have a challenge for you. Look past the obvious challenges of someone with a disability—whether it's a physical disability, mental disability, autism, or learning challenges—and make a new friend if you have the opportunity. And if you are a parent, teach your children that we all have certain strengths and weaknesses. Sometimes the weaknesses are just more visible and you have to look closer to see past them to see the good.

Follow Sharon's blog on www.kindnessmatters50.com/blog

Windlesham Rocks

The Windlesham Picnic is a highlight of this Surrey village's calendar. Historically, the event is held as a fundraiser for the amazing local charity, Woking Hospice, but this year for the first time, FOP Friends was chosen as a beneficiary too, in honour of local resident Isla who lives in the village.

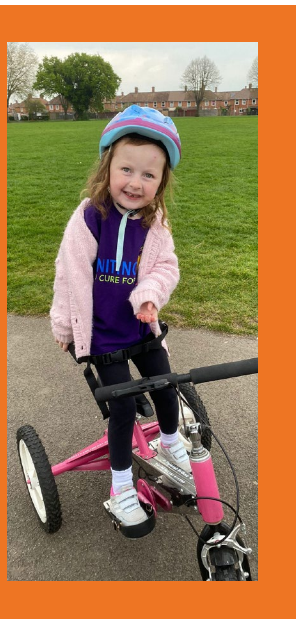
The picnic is an adult-only, evening event and has been running for 25 years. It is organised by a fantastic committee of volunteers, and many local businesses generously donate raffle prizes to help raise money for good causes.

The fancy dress theme this year was '100 Years of the BBC'. There were so many inventive costumes including 'David Attenborough' with his pack of penguins! Trustee Nicky and her husband James got into the spirit of the occasion by dressing up as Aunt Sally and Worzel Gummage! Live music was provided by the talented local saxophonist Bob Webb, with guests demonstrating their epic dance moves to the five-piece cover band !DAFT! It was an incredible event which raised £2000 funds for FOP Friends. A big thanks to everyone involved who made the picnic, an evening to remember!

Walk for Alanna

To mark FOP Awareness Day on 23rd April, Alanna's friends gathered at Victoria Park, Bridgwater, to take part in a charity walk.

Kids young and old took on the challenge to walk, scoot or ride around the park to raise awareness and funds for FOP Friends. Alanna herself took the lead, completing the full ten laps around the park on her specialist trike. Monies raised from the Walk, combined with previous events, means that Alanna and her friends have now smashed their target of £1000. A huge thank you to everyone involved. Go Team Alanna!



#FunFeet4FOP

Global Awareness Day 2022 saw facts and stories being shared across the world. We also got to see more of your creativity as you shared your #FunFeet4FOP.

23rd April is recognised and celebrated as FOP Awareness Day because it was the day the FOP gene discovery was announced. It was discovered after years of international collaboration. The exciting breakthrough allowed researchers to carry out their tireless work to find an effective treatment for those living with FOP and get us to where we are today.

Thank you to everyone who supported Global FOP Awareness Month and shared memes, messages and photos of their feet. Check out the fabulous socks from our friends Down Under at www.fopaustralia.org

FOP AUSTRALIA

Tell us your story

If you have a story to share about your life with FOP please get in touch. We'd love to hear from you.

We would also like to shout about any of your achievements and challenges you've done for FOP Friends.

Thank you to the following organisations for their generous support in funding the FOP Friends Together newsletter:

The February Foundation

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www.fopfriends.com

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Brilliant Becky

Long time supporter Becky Naylor ticked a huge event off her bucket list in April: the Boston Marathon!

Running in honour of her niece Jasmine, Becky flew out to Boston, USA, to take part in the world-renowned marathon. It's a tough race with what is described as an 'undulating route'. Whilst Becky had trained for hills, she hadn't quite expected so many hills and at such a late stage in the race! To a non-runner it might seem like running downhill is easy, but that really isn't the case. Run too fast down a hill and your quads will not be thanking you! Becky was determined to give the marathon her best, and she had the goal of doing her bit to help Jasmine to fire her on through the tough parts. People shouting out her name from her vest also helped to give Becky a boost. The best surprise of the event was her family, her cheer squad, appearing at the 19th mile! The weather was gloriously sunny and not ideal conditions for a marathon but seeing the city of Boston and the cheers of the crowds at the finish line made it the most incredible event. As well as smashing her own PB and getting an official time of 3:36:10, smashed her fundraising target, raising an incredible £1254!.

Not one to put her feet up, Becky has since taken part in a number of runs, including a Tough Mudder. Excitingly, Becky's next big race for FOP Friends will be the Great North Run where she will be running with her two sons Miles and Ethan – they're going to have to put some serious training in to keep up with their mum!

#LiveLaughLove in Slovenia

We were so happy to see the stunning photos from Nicky's wedding to James in picturesque Lake Bled, Slovenia – a truly joyous occasion. You may remember that Nicky and James had a ceremony last year in Windsor, but after 728 days of waiting, they were finally able to celebrate their marriage with a beautiful ceremony and blessing in the Church of the Mother of God. Surrounded by the emerald waters of Lake Bled, Nicky and James had the wedding of their dreams. It was made even more special with their children, family and friends joining them to share in the fairytale. Legend has it, that if you ring the bell three times, and make a wish, it will come true. Our wish is for a lifetime of happiness for the newlyweds and their family.

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