



friends[®] Together

Vol. 7 Iss. 3 Autumn 2024

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.

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One Tough Team!

Led by Oliver's brother Leo (14) and his cousin Eddie (14) (and their dads!), a 15-strong team took on Tough Mudder at stunning Heaton Park, Manchester, to raise money and awareness for our equally tough FOP warriors.

It was a dry and bright start to the day and the ground was remarkably un-muddy, but the challenges were still most definitely challenging! The team took on over twenty obstacles including scaling a wall, scrambling under barbed wired, swimming through below-freezing water and climbing to the top of the Mudderhorn! We're delighted to say they all made it round - just some faster than others - with Eddie the first from their group to cross the finish line.

Leo tells us,

“It was a great experience. I was a little nervous at the start, but further in I began to enjoy it and it was fun helping each other round. I had to push through some of the challenges but the best part was beating my dad to the finish line!”

Thank you to our team Carl, Carlos, Chris, Ed, Ethan, Joel, John, Liam, Matt, Max, Oscar and Phil, along with our three youngest team members Eddie, Leo and Lewis. You raised a terrific £3,800 for FOP Friends.



A word from Nicky



Welcome to the autumn issue!

The new school term is in full swing and I'm sure you'll agree our young people with FOP look fantastic! This season also marked the IFOPA's 'In Pursuit of a Cure: Day of Giving', a powerful fundraising effort to aid those with FOP, which we were very pleased to support.

After a rainy few weeks in the UK and numerous hospital appointments (unfortunately, Isla's respiratory health has worsened), I'm writing to you from the warmth of Lanzarote where we're currently at Swimlab, a hydrotherapy centre. Hydrotherapy, as many of you know, is one of the most effective therapies for those with FOP. We're focusing on breathing exercises and benefiting from the relief of warm, weightless water.

Thank you for your continued support of FOP Friends and I hope you enjoy this issue.

Warm regards,

Nicky, FOP Friends Trustee

Research Roundup

In our Spring 2024 Newsletter (Vol 7, Issue 1), we highlighted important new research published by Lounev et al (J Bone Miner Res. 39(4):382-398, 2024) reporting that a patient with typical FOP gene mutation, plus additional genetic mutations significantly reducing blood levels of a protein called matrix metalloproteinase-9 (MMP-9), developed very little extra bone (heterotopic ossification, HO).

This observation, and further research in multiple FOP mouse model studies demonstrating reduced HO when inhibiting MMP-9 by genetic, biologic, or pharmacologic means, led to a hypothesis that MMP-9 could be an important inflammatory trigger for Activin A-mediated HO in people living with FOP.

These observations and hypothesis suggest that MMP-9 inhibition may offer a potential novel additional therapeutic target for reducing HO formation in FOP patients beyond those currently in clinical development, which is exciting news.

Further good news stems from the fact that hundreds of patients, ranging from autoimmune diseases to cancers, have been treated with MMP-9 inhibitors in clinical trials so that we already have a knowledge of the safety profile with this class of agents.

Although there is the potential for off-target effects and no MMP-9 inhibitors so far investigated have been sufficiently efficacious to bring to market for the treatment of other diseases and conditions, having this kind of experience and data set will help facilitate conversations with regulatory agencies and should enable accelerated clinical trials in FOP.

āshibio

Exciting then that Ashibio, a California based start-up Biotech, have licenced Andecaliximab, a humanized antibody that specifically inhibits MMP-9, from Gilead Sciences who have previously administered it to approximately 1,000 patients in previous clinical trials for autoimmune diseases. Furthermore, Andecaliximab has been granted Orphan Drug Designation by both FDA and EMA for the treatment of FOP, meaning that Ashibio will receive additional regulatory support to advance more rapidly to the stage where they can apply for a marketing authorisation. Subsequent to discussions with FDA and EMA, Ashibio have set up a Ph2/3 clinical trial in people living with FOP, first in adults then young people above 12 years old in centres in Philadelphia, Minnesota and California in the first instance, due to start enrolment by the end of 2024.

Further interest in the potential for targeting MMP-9 for FOP treatment through re-purposing a tetracycline antibiotic, metrocycline, has been reported by Professor Robert Pignolo at our Conference back in May and discussed in more detail by Professor Fred Kaplan at the DDF in Sweden in June. There is evidence that metrocycline may indirectly inhibit MMP-9 by modulating certain signalling pathways involved in its activation; additionally, metrocycline has known anti-inflammatory properties, which could further contribute to its potential benefits for FOP patients. While direct evidence in FOP models have yet to be generated and no clinical trials are underway, this is certainly one to watch as an additional potential therapeutic possibility.

It is encouraging that there is a new player, Ashibio, now developing therapies for FOP, and particularly promising to have a new mechanistic target of MMP-9 inhibition with Andecaliximab entering an FOP clinical trial this year. Further studies with metrocycline are certainly also warranted - the more therapeutic approaches and options, the better for the FOP community!

To read Andrew's blog on MMP-9, visit: www.fopfriends.com/mmp-9/

How your fundraising helps...

We are ever thankful to our families, friends and supporters who fundraise tirelessly for us. For those affected by FOP, you give us HOPE. Through your generosity, we have been able to continue our support of the FOP research team, led by Professor Alex Bullock, at the University of Oxford. You can read their latest report and how your money is making a difference here: www.fopfriends.com/oxford/

We were also delighted to be able to make a gift of \$25,000 to the IFOPA's 'In Pursuit of a Cure' initiative in September. This global campaign united us with patient organisations worldwide, as we collectively work towards finding a cure for FOP. 100% of the money raised from this campaign will go directly to research which will further our understanding of FOP. It will also fund gene therapy programs, studies into flare-ups, and studies treatment options for pain management for those living with FOP.

To learn more about the campaign, visit: www.ifopa.org/curefop2024



Emerging Young Leader Award honour for Oliver

We were honoured and humbled to learn that Oliver had been recognised this year with the Jeannie Peeper Award for Emerging Young Leader. The Peeper Awards celebrate those who have made exceptional contributions to the worldwide FOP community through their leadership and service in raising FOP awareness.

Oliver, now 16, has been an advocate for those living with FOP since he was very young, attending his first fundraiser at Rochdale Town Hall with the Mayor when he was just three years old. When he was 10, Oliver gave his first presentation to a pharmaceutical company, and there's been no stopping him since.

Oliver continues to inspire people with his enthusiasm for life and perseverance, despite increasing challenges. He reflects, "I was genuinely surprised to receive this award," he said. "I have never expected any kind of award. I just try and do my part. If we can all do a little bit, all work together, then we will succeed in our fight to find a treatment for FOP. I am proud to be a part of this strong community where we all want the same thing."

You can read Oliver's full story, and meet the other Jeannie Peeper winners here: www.ifopa.org/2024_winners



Oliver, age 3, with Rachel, at Rochdale Town Hall, 2011

Horseback Heroine: Isla Receives Top Honour

As many of you know, Isla has a deep-rooted love for horses and riding. Isla goes to the Quest Riding for the Disabled group based in Chobham, Surrey. She attends a session every Sunday and it's one of the highlights of her week. While Isla adores all the horses, her best friend is Diablo.

Back in July, her dedication and perseverance were recognised with the prestigious Quest Zac Galt Memorial Trophy. Zac Galt was a young man whose unwavering determination and positive outlook helped him overcome life's challenges. Zac had cerebral palsy and was a dedicated volunteer at the group, supporting Isla on nearly every ride for five years.

Zac passed away unexpectedly in February of this year, leaving a huge hole in the hearts of everyone who knew and loved him. In his memory, Quest RDA named an award in his memory, which will recognise riders and participants who demonstrate the determination and perseverance that Zac embodied in his own life. It was a great honour for Isla to be the inaugural recipient of this very special award.

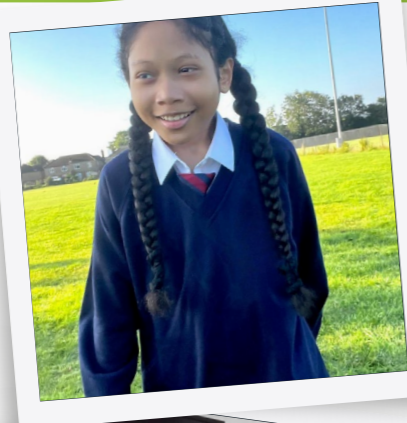
Isla's family was present to see her accept her well-deserved trophy. We're confident you'll agree that her commitment and resilience make her a perfect recipient. Congratulations, Isla! Your family, friends, and the entire FOP community are incredibly proud of you!



Trial Name	Sponsor	Drug	Status (UK sites)
Falkon	Ipsen	IPN60130	Ph2 Full
Progress	Incyte	INCB000928	Ph2 Full
StopFOP	Amsterdam UMC	Saracatinib	Ph2 Full
Optima	Regeneron	Garetosmab	Ph3 Full
Pivoine	Ipsen	Palovarotene	Ph3 Full
Andecal	Ashibio	Andecaliximab	Ph2/3 USA only Recruiting
Healthy volunteers	Daiichi Sankyo	DS-6016a	Ph1 Japan only Recruiting

Back-to-School 2024

The summer break is over, and it's back to school! We love to share photos as our kids head back to the classroom, all ready for the new opportunities ahead. From new backpacks and blazers to smiling faces and shiny shoes, let's take a look at some 'First Day of School' magic...



Meet Louise!

This edition's "Meet..." features the fabulous Louise!

Louise, who lives with FOP, lives in a picturesque coastal town on the northeast coast of Scotland. With a love of fashion and a strong commitment to advocating for those living with rare conditions, Louise is a true inspiration. So, let's hear a little bit about her story.

Can you tell us a bit about yourself?

Hello, I'm Louise, and I turned 31 in September. I'm passionate about helping others, whether through our church or in everyday life. My nieces and nephews bring me so much joy and keep me on my toes. I love cooking, fashion, organising, and anything related to gift-giving and party planning. I'm always on the go, and slowing down isn't exactly my strong suit!

We all know you as someone who has passion for fashion... Where did that begin?

It probably started when we were young - my mum always had us beautifully dressed. As I grew older, fashion became my creative outlet and the best way to express my individuality. I've never pursued a degree in fashion - or anything else for that matter. I'm more of a practical person than someone who enjoys theory. I'm full of useful but often trivial information!



What is your personal style, and has FOP influenced your fashion choices?

My personal style has evolved a great deal over the years, but it's always been about 'dopamine dressing' - wearing whatever makes me feel happy and confident. I've never let FOP define me, especially when it comes to clothing. If I love an item enough, I'll just get it altered or use my stitch gun - it's a lifesaver!

If it's not too embarrassing, can you share your worst fashion mistake??!

My teenage emo/punk phase definitely had some questionable fashion choices! I loved opaque colour tights and wore a lot of black. Thankfully, colour analysis in my 20s helped turn that around!

What items should everyone have in their capsule wardrobe as we move into AW2024?

A nice piece of knitwear and a suede work jacket are great, but practical staples for a girl living in the northeast of Scotland would have to include M&S Heatgen thermals - they're essentials!

Who are your fashion icons or role models, and how do they inspire you?

I wouldn't say I follow fashion as closely nowadays since my focus has shifted. I still enjoy keeping up with trends and watching influencers, though the women I follow now have more balanced content beyond just fashion.



What role do you think fashion designers and brands should play in promoting accessibility and inclusivity in the fashion industry?

Several years ago, I participated in a film to document the challenges and triumphs those living with a disability faced in the London fashion industry.

I think it's hard to make everything fully inclusive, given the range of disabilities. You can't please everyone. I often forget I'm disabled myself, which I'm grateful for. That said, accessibility is crucial and people today are more aware and open. In fashion, inclusivity is becoming more mainstream, with brands like M&S, Anthropologie, and ASOS leading the way demonstrating that inclusivity is possible.

We're not quite sure where you find the time, but we also hear you're a keen baker. What is your go-to recipe if you need to bake a cake to impress?

A firm family favourite is vanilla cake with white chocolate ganache and fresh raspberries.

It doesn't sound like you have much spare time, but what else do you enjoy doing?

I really enjoy serving at our church, whether it's in kids' ministry or through community work in our café and food bank. Life is always busy, whether it's something for the kids, catching up with friends and family, or whatever else we have planned. Some days are tough, but I power through with a positive mindset. My electric wheelchair has given me more independence, as I've never liked being stuck.

You've had the opportunity to be a 'Jeans for Genes' ambassador. Can you tell us more about your involvement and what you found most rewarding?

When the chance to become an ambassador came up, I jumped at it (back when I was more into social media). I loved the events but wasn't keen on public speaking. The most rewarding part was raising awareness about lesser-known genetic conditions, knowing it could help someone in the future.

Find us on social media

@FOPFriends

/FOPFriends

What do you want our readers to know about living with FOP?

Everyone's experience with FOP is unique. As a visual person, I found attending symposiums difficult because they offered a glimpse of what my future might hold. Growing up here, I've tended to isolate myself, but I've always had an incredible support system. I'm truly grateful for them as they've enabled me to live a full life without ever feeling excluded.

I truly feel that my journey has been shaped by these beliefs: maintaining a positive attitude; following a healthy, balanced diet; and having a supportive network in every aspect of my life.

I've always believed that whatever treatment or lifestyle path you choose, it's crucial to research and make informed decisions.

Squeeze the Day!

Aurora and her six-year-old brother, Benjamin, have been running a lemonade stand on their driveway for the past three years, dedicating each year's proceeds to a different charity.

This year, they chose FOP Friends in honour of their Aunt Louise. Despite the unpredictable Scottish weather, the sun shone brightly, making it a perfect day for their lemonade stand. Selling homemade lemonade and cupcakes, Aurora and Benjamin were overwhelmed by the generosity of their neighbours and even those who couldn't attend but still donated. Together, they raised an impressive £2,360.00 for FOP Friends.

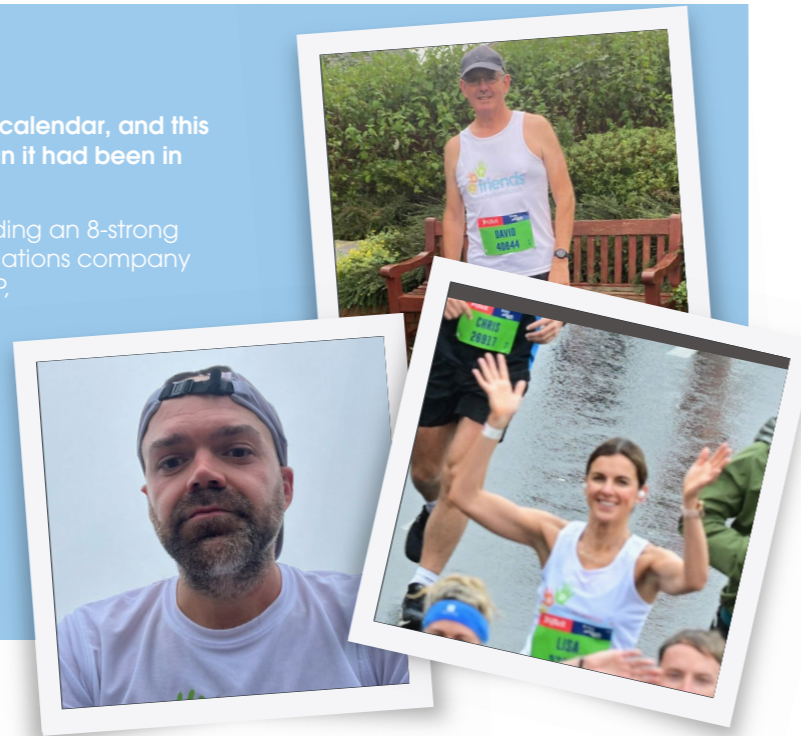


Team GNR

The Great North Run is one of our favourite runs in the calendar, and this year didn't disappoint – even though it was wetter than it had been in many years!

We had a fabulous team of runners taking part, including an 8-strong group from Bioscript. Bioscript is a scientific communications company who had worked with Chris. Learning more about FOP, they wanted to do something to help, so they gathered a team.

Our other runners were Lisa, who ran for her cousin, and last but definitely not least is David. David was running an impressive fourth Great North Run for us, in honour of Isla: you are a hero! Thank you to everyone for their training, commitment and generous friends. Team FOP Friends raised £4,103! **If you would like to take part in GNR 2025, get in touch.**



The Big Half is a Big Success!

They say if you want something doing, ask a busy person... well, Izzy has most certainly been busy this year, including graduating from university. Despite this, she still managed to find time to train and run a half marathon to raise money for her sister Annabel. Izzy tells us how her sister inspired and motivated her to cross that finish line:

On the 22nd of April, I signed up for the London Big Half Marathon to run for FOP Friends, and my sister Annabel who has FOP. I was in my last year at Durham University, juggling my dissertation, exams and university life. I had been aware of the incredible work FOP Friends does in raising awareness and supporting research for FOP, but participating in the half marathon gave me the perfect opportunity to make a meaningful contribution. Running a half marathon had always been a personal challenge, but the chance to combine that goal with supporting a charity like FOP Friends made the experience all the more significant.

I started my training block in June, ahead of the half marathon on September 1st, however, I had to postpone it for a month due to an injury. The training process was demanding but rewarding. Having a structured routine kept me focused and motivated, even on the tougher days when I wasn't sure I'd make it to the finish line. Each step forward felt like progress not just for me, but for the cause. As I trained, I learned more about FOP and the challenges those affected face, fuelling my determination to make a difference.

One of the highlights of this journey was witnessing the overwhelming support from friends, family, and even strangers. **Their encouragement and generous donations helped me raise £2,460, surpassing my original target.** I felt proud knowing that this money would go towards research and support for those with FOP.

The race day itself was unforgettable. From the energy of the crowd to the camaraderie of fellow runners, the experience was both exhilarating and humbling at times... Crossing the finish line was a deeply rewarding moment, not just for the personal achievement but for the knowledge that I had played a part in supporting such a vital cause.

It was a day and experience that will not be forgotten, and I hope I can continue making a difference for this amazing charity and Annabel.



A Motoring Adventure

Now that summer's sun has set, our friend Hamish shares a tale from one of his day trips and reviews the British Motor Museum in Warwickshire, looking at its accessibility for visitors with additional needs.

Like many of us, navigating life with FOP presents unique challenges, particularly when it comes to venturing out for appointments or social engagements. My condition places me in an unusual predicament: I can neither walk for extended periods nor sit down or utilise a wheelchair.

This rare combination of limitations has compelled me, like many others with FOP, to cultivate resilience and seize opportunities when they arise. Traversing uneven terrain is a significant hurdle, with grassy areas and slick surfaces impossible. The process of finding suitable destinations becomes a complex puzzle, further complicated by the capricious nature of British weather.

Despite these obstacles, I've maintained a lifelong passion for cars. This enduring interest recently led me to embark on an excursion to the British Motor Museum, an adventure that merged my love for cars with the ongoing challenge of managing my condition.

Nestled in Gaydon, a quaint Warwickshire village, the museum is set within 65 acres of meticulously landscaped grounds, seamlessly blending into the picturesque Warwickshire countryside. The main museum building captivates visitors with its stunning art deco architecture, while the adjacent Collections Centre offers a striking modern counterpoint.



The museum offers excellent accessibility features, making it a welcoming destination for visitors with diverse mobility needs. Ample parking is available, including conveniently located disabled spaces near both buildings. For younger, able-bodied visitors, there's an adventure playground to enjoy.

While the museum provides wheelchairs for guest use, I found the polished concrete flooring manageable with assistance from my carer, allowing me to explore at a leisurely pace. The main building features a lift to access the café, though I didn't personally test it.

Housing the world's most extensive collection of historic British automobiles, the museum showcases an impressive array of vehicles. From iconic Minis to luxurious Rolls-Royces, the exhibits span from the early 1900s to contemporary models. The thoughtful layout of the exhibits provides generous space between vehicles, facilitating easy movement and viewing.

Among the standout displays are the exhilarating rally cars and the unique City cab from the film 'Judge Dredd', ingeniously built on a Land Rover chassis. The Thunderbirds limousine, a striking 2004 creation by Ford, proved popular for many visitors as did the iconic Reliant Robin featured in the timeless classic 'Only Fools and Horses'.

The second building is accessible via a spacious ramp. To minimize my walking distance, my carer reversed my van halfway up the ramp before relocating it to a parking space. Inside, a generously sized lift, provided convenient access to the upper level.

The first floor is a treasure trove of automotive history, showcasing an eclectic mix of vehicles ranging from classic vintage models to truly unique specimens. As you step out of the lift, you're greeted by a mezzanine area



that offers a fascinating behind-the-scenes glimpse. From this vantage point, visitors can observe the meticulous process of vehicle restoration and preparation for display.

During my visit, I had an enlightening conversation with one of the museum's curators, who shared valuable insights into the decline of the once-mighty British motor manufacturing industry. The curator explained that renowned manufacturers such as Rover, Leyland, and Austin struggled to evolve with the times. Their inability to embrace and integrate technological advancements, ultimately contributed to their downfall in the ever-changing landscape of automotive production.

The final Rover 100 built, signed by the 1200 employees which contributed to its manufacturing lay testament to their failings.

Reflecting on my experience, the visit to the British Motor Museum proved to be a good outing, despite some challenges.

The extensive walking required, due to the size of the site, pushed me to the limits of my comfort, surpassing what I'm typically accustomed to. While I couldn't explore every exhibit personally, my attentive carers captured photographs which allowed me to enjoy the displays I missed vicariously.

A particularly appealing aspect of the museum's offering is their year-long admission ticket. This thoughtful option opens the door for a return visit. This will allow me to spread out the experience, making it more manageable given my physical limitations, whilst also giving me something to look forward to next year. Just like Arnie said, 'I'll be back!'

Visit: www.britishmotormuseum.co.uk

It's never too early!

We're excited to launch the new design of our Christmas Card for 2024!

This year, our card has been designed by the lovely team at Haywood Sener Designs. Beril and Emma are always keen to support small charities close to their hearts, and this year they wanted to do something to help out their special friend Isla. We do hope you like this year's fun design!

Keep an eye out on our socials for when they are ready to ship!
www.fopfriends.com/shop



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The Zochonis Charitable Trust.



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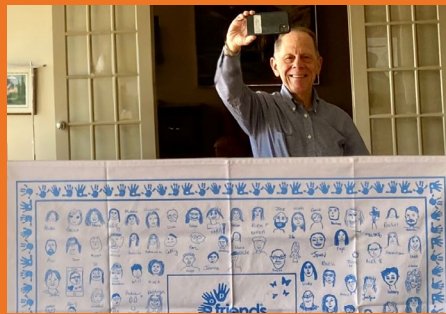
FOP Friends is registered with the Fundraiser Regulator, an independent self-regulatory body for the UK fundraising that encourages commitment and compliance with best practice in fundraising.

We hope you enjoy receiving our newsletter. However, if you no longer wish to be on our mailing list, please email us at info@fopfriends.com

Totally tea-voted!

OK, so we're still buzzing after our Conference!

Because the event is so special to our families, we make commemorative tea towels for attendees. Shipping them around the world is most definitely a labour of love!



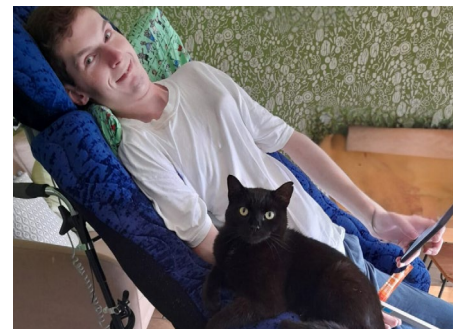
Unfortunately, Professor Fred Kaplan wasn't able to join us this year, but in recognition of everything he continues to do for our community, we popped one in the post for him! He was surprised and delighted to receive it!

If you'd like to see the gallery of photos from our event, just scan the QR code. We're already working on a date for 2026 so get your diaries at the ready...



Graduation Success!

Please join us in congratulating Rohan who has graduated with a BA (Hons) in Criminology with Sociology from the University of Northampton. His dedication and hard work have paid off, and his family couldn't be prouder of his achievement.



Rohan has always had a curious mind and a constant need to ask 'why', whether it's to others or himself. He explains it as a simple yet powerful word: 'Why did you do that?', 'Why do you feel that way?', or sometimes 'Why did my actions/ words make you feel that way?'. Rohan wonders if his fascination with this question stems from his disability (as many people with a disability often think about why able-bodied people act the way they do around them). Or perhaps it's simply a morbid curiosity?

It is this 'why' which Rohan found to be one of the most intriguing aspects of criminology and may even have led him to this path. He tells us, "I'm fascinated with this central question, focusing on why criminals commit crime and why society is often structured in a way that traps people into believing crime is the only escape."

While Rohan loved his studies and had amazing professors as well as support, the most rewarding part was the 'University Life'. He shares, "I'm lucky to have a supportive family, including two progressive parents and a sibling who's a nurse. However, living away from home for the first time was refreshing. This newfound freedom allowed me to explore my identity, experiment with relationships, and form friendships with my brilliant flatmates."

As Rohan looks ahead, he is actively seeking career opportunities in the field of criminal research, either hybrid or work-from-home. He is also keen to volunteer his time to mentor and support children who are survivors of familial abuse, using his knowledge and experience to make a positive impact on their lives.

We wish Rohan every success as he embarks on this new journey and look forward to seeing what he accomplishes in the future.