CGF News

March 2023

Making a difference wherever growth is a concern

Child Growth Foundation
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Please consult your medical practitioner / health care professional for confirmation and/or advice.
Our team

Child Growth Foundation staff

Laura Roy
Finance & Admin Manager
laura.roy@childgrowthfoundation.org

Sally Majid
Growth Nurse Specialist
sally.majid@childgrowthfoundation.org

Catriona Taylor
Charity Manager
catriona.taylor@childgrowthfoundation.org

Child Growth Foundation trustees

Jeff Bolton
Chair
jeff.bolton@childgrowthfoundation.org

Jessica Watts
Vice-Chair
jessica.watts@childgrowthfoundation.org

Steve George
Treasurer
steve.george@childgrowthfoundation.org

Laura Cadd
Trustee
laura.cadd@childgrowthfoundation.org

Nick Child
Trustee
nick.child@childgrowthfoundation.org

Anthony Leyton-Thomas
Trustee
anthony.leyton-thomas@childgrowthfoundation.org

Rachel Pidcock
Trustee
rachel.pidcock@childgrowthfoundation.org

Linda Washington
Trustee
linda.washington@childgrowthfoundation.org

Clare Wood
Trustee
clare.wood@childgrowthfoundation.org
From our Chair

It was a pleasure to meet so many members in September last year, during the CGF convention in Warwick. It was my first CGF convention and I learned so much from the expert sessions, and I really enjoyed and appreciated the great sense of community amongst the families present.

The CGF annual general meeting (AGM) provided the perfect opportunity to express our sincere appreciation of their huge contribution and commitment to the organisation of two key staff members who were stepping down: Neil Hunter, who brought significant expertise and was pivotal to the day-to-day running of the organisation, and Jenny Child, who had provided immense support and guidance to families for over 20 years. The AGM also provided the opportunity to formally welcome and introduce Sally Majid, CGF’s Growth Nurse Specialist, and announce the much deserved progression of Laura Roy into the role of Finance and Administration Manager, and the appointment of Jessica Watts as Vice-Chair and Steve George as the new Treasurer. It is also my pleasure to now introduce and welcome our new Charity Manager, Catriona Taylor, who brings a wealth of charity expertise and experience to the CGF.

All CGF staff and trustees are looking forward to delivering our exciting plans for 2023. We will continue to provide and, where possible, expand support and guidance to families, whatever their growth concerns. We want to focus more of our efforts on raising public awareness and understanding of growth conditions, and we have already initiated the development of suitable advertising and PR campaigns. We will also expand our range of educational support and materials and will investigate more digital opportunities.

We will intensify our campaigning for the earlier detection, diagnosis, and referral of growth conditions to the appropriate specialists. We plan to be more pro-active in the petitioning of key first-line stakeholder groups, and to play a key role in informing school staff and nurses and driving a campaign to improve child measuring.

The CGF will continue and, where appropriate, instigate and contribute to the development, expansion, and evaluation of the clinical evidence and research to support and justify the treatment of growth conditions. We will both instigate proposals for new growth studies and, when our funds permit, will develop and deliver our own.

We know our plans for 2023 will require us to revitalise and expand our fundraising efforts. We hope we can build on our strategic partnerships with companies who will support us, and we will roll out a year’s programme of fundraising activities. We also hope it will be possible to involve many more CGF members and volunteers in our activities, and we will be grateful for any support you can give us.

I look forward to meeting many more of you during 2023.

Best wishes to all,

Jeff Bolton
Hello from Catriona

I joined CGF in October 2022, and what a fantastic first few months it’s been! Everyone has made me feel so welcome and I’m really looking forward to the year ahead, including attending my first CGF convention this October.

I’m based up in Newcastle where I live with my husband Frank, our five year old son Finn and our one year old daughter Erin. I joined the charity sector back in 2010, originally as a volunteer for a cancer charity, following my mum’s cancer diagnosis.

She fortunately went into remission and I was delighted to start my career in the charity sector shortly afterwards, working for over nine years for blood cancer charities, focusing on funding research and providing patient support. I subsequently joined a regional children’s charity and a befriending charity and have always been so humbled by the passion, dedication and enthusiasm people have to come together as a community to support others and to support each other. I’m delighted to be part of our CGF team and I’m really excited for the months and years ahead, working together to support children, adults and families.

The latest edition of our newsletter has updates from familiar faces, new patient stories, details of upcoming fundraising activities and events for 2023, stories of brilliant support we’ve received for our work, details of our 2023 convention taking place 6th-8th October, and lots more!

I’m looking forward to meeting many of you in 2023, in person or digitally. If there’s anything you’d like to discuss I’d love to hear from you at catriona.taylor@childgrowthfoundation.org or on 07492 562221.
Update from Sally

Growth Nurse Specialist
sally.majid@childgrowthfoundation.org

It was fantastic to be part of last September’s annual convention and finally meet and chat to so many members old and new, albeit with a tinge of sadness that it was Jenny and Neil’s last CGF convention before they left us for pastures new. The weekend was busy, but incredibly rewarding to hear how much everyone enjoyed it. If you haven’t attended before, I can fully recommend it as an informative weekend of fun!

We are very excited that Catriona Taylor has joined the CGF team and have spent time planning how we can maximise our resources to ensure our activity benefits current members as well as those affected by growth conditions who have yet to reach us.

Shortly after the convention, I spent the day observing the endocrine clinic in Nottingham where I learned more about how the endocrine team works. I found it incredibly helpful to understand how children are assessed and subsequent treatment plans are made. I’m very grateful to the team at Nottingham University Hospitals and particularly the parents and children who allowed me to sit in on their appointment.

Our Growth Measurement Survey is now live and has so far been completed by 34 healthcare professionals. It would be fantastic if you could pass on the survey link to anyone you know who works with children in a healthcare setting.

The link is available on our website here: www.childgrowthfoundation.org/hcp-survey
In November you may have seen that Jeff and I attended the BSPED Annual Meeting in Belfast. It was wonderful to connect with so many clinicians, pharmaceuticals and other charities again, to share our resources and discuss how we can work together.

We have since been speaking with The Pituitary Foundation about a recent survey they worked on with Consilient Health around stim tests for adults being investigated for Growth Hormone Deficiency. Consilient Health is a pharmaceutical company who have produced a new diagnostic test for GHD – they hope to get this test licensed for use in children and want to work with us to identify the patient experience of stim tests for children and young people. I will keep you all informed of how this progresses.

Our support line

Need to speak to someone? Our telephone support line is available to anyone concerned about their child’s growth or if they have a diagnosed growth condition. We are here to listen and support you.

Call us on 020 8995 0257.

Our staff work on a part-time basis. If we are not able to answer your call please leave a message and we will get back to you as soon as possible. Alternatively please email our support email at support@childgrowthfoundation.org to arrange a time to chat.

Links and resources

At the CGF we’re really proud to work collaboratively with others with a shared goal of providing support and information.

As part of this we are looking to add a page on our website sharing links to related groups, charities and organisations along with highlighting useful external resources like publications, videos and podcasts.

If there are any sites, pages or resources that you have accessed in the past that you think would be useful to others in our child growth community we’d really appreciate if you could please share these with us at info@childgrowthfoundation.org.
ANNUAL CONVENTION and AGM

6th-8th October at Delta Hotels by Marriott, Warwick

The CGF convention is back! We're already so excited for this year's event and we'd love to see you there.

This year's event will be returning to Delta Hotels by Marriott, Warwick and as the event is being held in October we have set the spooktacular theme of... Halloween!

New for 2023, convention will be open to non-members. Members will have early-bird access to convention and will receive a member goody bag for the event. We hope by opening the event to non-members too we can reach as many people as possible, to support children, adults and families affected by growth conditions.

You will soon be able book and pay to attend the event on our website at www.childgrowthfoundation.org/convention

The full itinerary will be made available online as plans progress over the coming months. If you would like an offline version of the booking form please contact us at info@childgrowthfoundation.org.

For those arriving on the Friday evening we will have entertainment provided. We will have activities planned for children and young people throughout the Saturday alongside our sessions run by experts and specialists who will present, discuss and answer any questions on many topics, including updates on any latest research and treatment options.

There will also be plenty of time for networking and socialising with others, and we're so pleased that Tom Wyllie will be joining us again, entertaining us throughout the Saturday evening. New for this year we will also be holding optional sessions on the Sunday morning before you head home.

If you wish to stay in the hotel, please book by calling the hotel directly during office hours on 01926 499 555 option 2 and quoting the Child Growth Foundation convention. As accommodation bookings are made directly with the venue, they set the room pricing which has increased for 2023. However, they have worked to minimise the impact of the increase on our attendees.

We have kept our convention attendee rates the same as 2022 and hope to see familiar faces and new families too joining as we all come together for our special CGF weekend.

We are seeking feedback and input on convention to make it the best possible event for everyone attending. If you have or haven't attended before we’d really appreciate if you could spare a few minutes to complete our short convention survey at: https://bit.ly/cgfsurvey
We will be holding a raffle and tombola throughout the Saturday at convention, as well as having our CGF stall selling goodies. If you have any prizes that you would like to donate, please let us know or bring them along with you. Please note that we are only able to accept new items.

Kate’s Bursary

We are extremely honoured and grateful to the family of Kate, who had been members of CGF for many years. Kate had a growth condition and attended the annual conventions as a child and teenager, appreciating the information and support.

Sadly, Kate died in 2019. In her memory, Kate’s parents would like to provide funds of £500 a year to enable a family to attend our convention, who might otherwise be unable to afford to do so.

The bursary for the 2023 convention will be for a maximum of £500 and can include: cost of convention, hotel accommodation, convention childcare and reasonable travel. Travel expenses will only be paid once proof has been provided. This is open to both members and non-members of the CGF. If you do not currently have CGF membership and are awarded the 2023 bursary a one-year CGF membership will also be provided to you.

The staff and trustees of the CGF will review all eligible applicants and their decision will be final. The CGF will let all applicants know if they are unsuccessful but will not provide reason. All information provided will be kept strictly confidential and follow GDPR legislation. If you have already booked to attend the convention, you can still apply and your application will be considered, following the same criteria. If you are successful, any money already paid by you to the CGF for convention will be refunded.

If you think you might be eligible for this year’s bursary and would like to apply, please email catriona.taylor@childgrowthfoundation.org with the following information:

- Full Name
- Address
- Person’s name with the growth condition and their date of birth
- Email address
- Telephone number
- A short statement as to why/how you would benefit from this bursary

Deadline for applications will be 1st June 2023 and the successful applicant will be notified by 30th June 2023. Many thanks again to Kate’s family for this wonderful support in her memory.

Notice of AGM

Notice is hereby given that the Annual General Meeting of the members of the Child Growth Foundation will take place on Saturday 7th October 2023 at 9.30am at Delta Hotels by Marriott, Warwick.

We will be holding a raffle and tombola throughout the Saturday at convention, as well as having our CGF stall selling goodies. If you have any prizes that you would like to donate, please let us know or bring them along with you. Please note that we are only able to accept new items.
BSPED Growth Disorders Special Interest Group update

Professor Helen Storr
Chair and Coordinator of the BSPED GD-SIG

As you might remember from previous newsletters, in 2020, we created the National British Society for Paediatric Endocrinology and Diabetes (BSPED) Growth Disorders Special Interest Group (GD-SIG).

The mission of this group is to improve the recognition, diagnosis and management of growth disorders in the UK and to coordinate research and education in this field. Our hope is to provide a focal point for clinical staff, patients and families nationally and put growth disorders on a level footing with the other major endocrine disorders affecting children.

In 2022, the membership increased to 16 with wide representation from around the UK including several individuals well known to the CGF (Professors Helen Storr and Justin Davies who are Chair / Deputy Chair of the group, Dr Renuka Dias and Jenny Child). Since the last newsletter, two important national position statements have been completed by the group. These have been adopted by the BSPED and uploaded to the official website:

'Clinical standards for growth assessment and referral criteria for children with a suspected growth disorder' [link]

'The aim of the first document is to provide guidance on how best to measure children, monitor growth and, importantly, when to refer.

The second aims provide standards for the initial clinical assessment, investigation and genetic testing of children with short stature. We hope these documents will raise awareness and improve the recognition and diagnosis of childhood growth disorders.
Following finalisation of the ‘Clinical Standards for GH treatment of GH deficiency (GHD) in Childhood and Adolescence’ which was published on the BSPED website last year www.bsped.org.uk/media/1980/clinical-standards-for-gh-treatment-of-ghd-in-childhood-and-adolescence.pdf, we are currently working on recommendations for the other conditions treated by growth hormone and a specific statement on the treatment of Silver-Russell Syndrome with growth hormone. I hope I can share these with you later this year.

Our next meeting is scheduled on 31st March 2023 where we will discuss our plans for this year. If you would like to get in touch about the group or would like to put forward some ideas for discussion, please contact me (h.l.storr@qmul.ac.uk) or Jenny (jenny.cgf@me.com) by email.

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**Paediatric adrenal insufficiency consensus guidelines launched**

The new British Society for Paediatric Endocrinology & Diabetes (BSPED) consensus guidelines on the emergency and peri-operative management of adrenal insufficiency in children and young people were recently launched at the annual BSPED conference in Belfast in November 2022.

These have been developed by the Paediatric Adrenal Insufficiency Group on behalf of the BSPED.

They should provide an invaluable resource for patients, families and clinicians as they provide practical advice for managing steroid treatment during illnesses, emergencies, major and minor surgery.

There is a dedicated page on the BSPED website www.bsped.org.uk/adrenal-insufficiency and through the QR code above.
At the Child Growth Foundation we are privileged to have the following health professionals advise and support us with the work that we do. Our experts help create the information and booklets you see on our website and are regular speakers at our annual convention.

If you have queries regarding you or your child’s treatment we recommend you speak to your consultant in the first instance. If you need further advice please contact our support line. For any queries we are unable to answer we will seek an expert opinion on your behalf.
We are extremely grateful to have a group of experts in the field supporting our work as Medical Advisors of the Child Growth Foundation.

We are pleased to share an opportunity to join our panel of Medical Advisors in 2023. This voluntary role requires a small input in terms of hours but has the potential to have a great impact on our work and the people we support.

Our Medical Advisors will be invited to join virtual bi-annual meetings with our friendly staff team and fellow Medical Advisors. Some of the ways our Medical Advisors help us can include:

- Providing medical content or scientific updates for our communications including our bi-annual member newsletter
- Providing expert knowledge and advice that will help us to better support children, adults and families
- Supporting and expanding our charity’s work and our presence to raise awareness of child growth conditions

We have a strong range of skills and knowledge within our current panel of Medical Advisors and we are keen to expand this to include knowledge and expertise from professions such as:

General Paediatrician
School Nurse
Health Visitor
Endocrine Nurse
General Practitioner
Pharmacist
Psychologist

To register your interest in becoming a Medical Advisor at the Child Growth Foundation please send your CV and covering letter to Catriona at catriona.taylor@childgrowthfoundation.org.
**Background**

Treatment with daily GH injections has been a mainstay in the management of GHD for close to 40 years.

Since 2022, the options for management have changed in that there is now the availability of a Long-Acting Growth Hormone (LAGH) formulation that is given once weekly.

Somatrogon is recommended, within its marketing authorisation, as an option for treating growth disturbance that is caused by growth hormone deficiency in children and young people aged 3 years and over.

Following recent marketing authorisation by NICE – [www.nice.org.uk/guidance/ta863](http://www.nice.org.uk/guidance/ta863) – clinicians can consider Somatrogon from one of a range of suitable treatments that are available (including any preparation of somatropin) and discuss the advantages and disadvantages of GH products/devices with parents, carers, children and young people.

The decrease in frequency of injection provided by LAGH has the potential to improve adherence and has the potential for better patient engagement and concordance with treatment, potentially maximise efficacy related to improved treatment outcomes and offer increase flexibility for children and young people.

Evidence from clinical trials has demonstrated that Ngenla (LAGH) is as effective as one preparation of somatropin (Genotropin) with non-inferior annual height velocity achieved.

Weekly administration of LAGH was generally well tolerated in paediatric patients with GHD and the most commonly reported treatment related adverse event was injection site reactions.

Injection site reactions included an increase in injection site pain and erythema.
**About Somatrogon (Ngenla)**

Ngenla is available in a pen-device with two strengths of formula available – 24mg pen and 60mg pen. The device is pre-loaded with the GH medicine and premixed and is disposable following use.

The 24mg pen can administer doses in increments of 0.2mg that range from 0.2mg to a maximum dose of 12mg per dose actuation.

The 60mg pen can administer doses in increments of 0.5mg that range from 0.5mg to a maximum dose of 30mg per dose actuation.

Both formulations contain 1.2mls of solution per pen device. The recommended dose is 0.66 mg/kg body weight administered once weekly by subcutaneous injection.

Each pre-filled pen is capable of setting and delivering the dose prescribed by the clinician. The dose may be rounded up or down based on the clinician's expert knowledge of the individual patient needs.

When doses higher than 30 mg are needed (i.e. bodyweight > 45 kg), two injections have to be administered on the same day.

Ngenla dose may be adjusted as necessary, based on growth velocity, adverse reactions, body weight and serum insulin-like growth factor 1 (IGF-1) concentrations, which should be checked 4 days after the prior dose of Ngenla.

Both the 24mg and 60mg Ngenla device use a standard 5mm needle for administration (4mm-8mm needles can be used with 31-32G) and the pen devices do not have a needle cover/guard.

Ngenla is stored in a refrigerator between 2 and 8 degrees and can be taken out of the fridge before use and held at room temperature for up to 4 hours. The pen can be used for up to 28 days after the first use (first injection) before it needs to be discarded.

The weekly dose of Ngenla can be changed if needed and it is recommended that there are at least 3 days since the last dose. Ngenla can therefore be given up to 3 days past the normal dosing day.
Alder Hey experience of Somatrogon (Ngenla)

Since autumn 2022 we have been prescribing Ngenla for some patients with a diagnosis of GHD. The decision to prescribe Ngenla has been based on clinical diagnosis and within the licensed indication > 3years.

Key factors have included both the eligibility of patients who may be considered for a LAGH formulation and following a discussion concerning choice and the preference of the child, young person and their family.

Selecting the most appropriate pen size is important to ensure adequate weekly dosing and to minimize potential wastage of medicine where possible. The recommended dose is 0.66mg/kg body weight and to ensure adequate dosing the dose is rounded up when needed. For patients with a body weight >45kg patients are counselled that they will need two injections given on the same day once weekly as the maximum dose actuation with the 60mg pen is 30mg per injection.

The use of the pen is relatively simple. Training and education of children, young people and their families usually takes a similar amount of time as to the standard daily GH formulations.

Needle covers/guards are not available, for some patients switching from a daily GH formulation this has been a feature that they have on occasion noticed and provided comment.

The volume of medicine per injection is more than with the standard daily GH formulations. This can result in a slightly longer period of injection following administration.

Some patients have complained of minor discomfort but not significantly more than with the standard daily GH formulation.

We have also been arranging for patients to have a blood sample collected for IGF-1 measurement approximately 6 weeks following initiation of treatment, 4 days following their last injection of Ngenla.

Overall, patients have reacted positively to this new GH formulation, reduced burden associated with frequency of injection has been welcome.

In terms of response to treatment we do not have any patients that have been on Ngenla longer than 6 months and we will continue to evaluate the efficacy and safety at approximately 6 to 12 month intervals and assessed by evaluating auxological parameters, biochemistry (IGF-1, hormones, glucose levels) and pubertal status.
Mental Health Resource Project
Developing a mental health resource for young people living with an undergrowth condition

The Child Growth Foundation wants to provide more psychological support for young people living with a growth condition.

As part of this ongoing work we have launched a project to find out more about young peoples’ experiences of mental health and living with an undergrowth condition.

We have teamed up with health psychologist Dr Lisa Hodges from Cognitiva Consultancy Ltd, whom the Child Growth Foundation have worked with before, to develop a questionnaire with a focus on undergrowth conditions.

The findings will be used to create a resource to help young people who are struggling with poor mental health.

Who should fill this in? We are looking at the experiences and views of young people aged 11 to 25. There are a few questions for the parents/careers/guardians of young people and their views on young peoples’ experiences.

Anonymity & confidentiality: All answers will be kept completely anonymous (not identifiable) and confidential (private) and many people’s answers to each question will be combined, so no one will find out what each person has said. You may not even be able to spot your own answers.

Other benefits of taking part: You may find it helpful to write about your experiences. Writing about your experiences here is an opportunity to raise awareness and what you write may help another young person.

Where will my answers go? Will they be safe? All your answers will be kept safe with the Child Growth Foundation and Cognitiva Consultancy and will only be seen by the team working on this project.

To receive a copy of the questionnaire and the supporting information pack including a Q&A for families, please contact Catriona at catrina@childgrowthfoundation.org.

To express our thanks for taking part in this study, a £20 Love2Shop e-gift card will be provided to the first 20 young people who complete the questionnaire.
Fundraising news

Trustee Anthony Leyton-Thomas takes on his second CGF marathon

This year, I am running the London marathon by accident. In 2021, I did it deliberately, with a charity place kindly given to me by the CGF. I raised a couple of thousand pounds, cleared the finish line in under four hours (hurrah), and ticked a box on my bucket list. Boom. No need to do that again.

Trouble is, they’re sneaky. If you apply to run the London Marathon and choose to donate your entry fee, they send you a rather snazzy running top if you don’t get a place. And given there are millions of applicants for around 50,000 places, you’re almost certain not to run. The 2023 ballot opening coincided with me deciding I could do with a new top for the winter months, so I entered, with the cast-iron certainty that I wouldn’t get a place, but I would get some lovely – and surprisingly good value – new exercise gear out of it.

Three weeks later, the email arrives: ‘You’re in!’ Whoops. That backfired.

My wife Jacqueline is, as ever, a fountain of support: ‘So you entered a marathon you’ve already done, that will mean you’re disappearing off to train every other day for months, leaving me with the four kids, at a time when we’re not only trying to move house, but also move city, without so much as consulting me, because you wanted a geeky jacket that you could have just, y’know, bought?’

The answer to this question, inescapably, is: yes. It sounds – as it always does when she says it – as though I haven’t been thinking rationally. For a moment I wonder whether the most gracious course of action would be to withdraw, but then a lightbulb pings on somewhere in the murk of my brain.

‘It’s for... it’s for the Child Growth Foundation.’ Checkmate. She wouldn’t argue with a children’s charity. What is she, some kind of monster? The argument is nipped in the bud, I get to spend a Sunday in April leaning into my middle-aged running habit, and maybe we’ll get some cash in the CGF coffers in the process. Everybody wins, with the possible exception of my wife.

Our family has been involved with the CGF for the last five years, since our son Ivo was diagnosed with Sotos Syndrome at the age of five. The foundation was a tremendous source of support and information for us when it came to navigating the confusing world of Ivo’s condition. That’s why I’m proud to have been able to use fundraising for the CGF as my excuse for indulging my mid-life crisis on several occasions over the last few years.
Towards the end of 2021, I was invited to join the board of trustees – which, I like to think, is the forty-something dad’s equivalent of an elite athlete being offered a Nike sponsorship deal. At first, I was a little anxious about accepting; I was under the impression that charity trustees were all hugely gifted, desperately clever pillars of society with a plethora of professional skills and a dedication to saving the world. Now, after a year in the role, I am pleased to report that this is not the case – and not just because I joined the team.

Joking aside, the CGF board is a fantastic bunch of people, from all walks of life, united by personal or professional experience of dealing with growth conditions in children. Any concerns I had about ‘being qualified’ to be a trustee were rapidly alleviated, as I realised the board had built a culture where all views were valid, everyone was listened to, and in which everyone was free to be themselves and make their contribution without fear of being judged. There is work to be done of course – this has been a hugely busy year for the CGF, with a lot of changes and new faces on the scene (mine included) – but it’s also been a lot of fun to be involved, and hugely rewarding to feel as though I’m making a difference, however small it might be.

And making that small difference is why I’m happy to be ‘annoying charity guy’ in my friends’ Facebook feeds yet again; why I’ll be pulling myself out of bed early on a weekend morning for the next few months to get the miles in; why I’ll be boring my family to death yakking on about marginal improvements to VO2 max and resting heart rate, and why, on the morning of Sunday 23 April, I’ll be stood on Blackheath with 50,000 other people, to start a race I’ve already run, for a cause I’ve already fundraised for – and I won’t even have that snazzy top to show for it.

You can sponsor Anthony at www.justgiving.com/anthonyleyton

Interested in becoming a CGF trustee? We’re always on the lookout for enthusiastic people to help take our charity forward. We’re particularly keen to hear from anyone with the following skills: Digital, Fundraising, HR and CSR, although they’re not essential. Please get in touch with Catriona to find out more at catriona.taylor@childgrowthfoundation.org.
Ways to get involved

Thank you so much to everyone who supports the Child Growth Foundation. There are so many ways to help: one-off donations, regular giving, online fundraising including Facebook Fundraisers and JustGiving pages, offline activities like cake sales and sponsored challenges, taking part in CGF events, providing grants, buying items from our shop, and last but by no means least, CGF membership.

We’re extremely grateful for all the different ways you raise funds for our charity and the work this enables us to deliver. With support like this, we can continue to evolve to support children, adults and their families with newly diagnosed conditions, as well as those seeking diagnosis.

Here we’ve included some upcoming and ongoing ways to get involved. If you’d like to support us or discuss any ideas, we’d love to hear from you! Please get in touch with us at fundraising@childgrowthfoundation.org.

Are you based in or near Newcastle upon Tyne? We have the opportunity to hold a fundraising bucket collection at Tesco Extra at Kingston Park, Newcastle. If you may be able to volunteer for a few hours, please get in touch with us at fundraising@childgrowthfoundation.org and we can arrange a suitable date with the store.

Ink cartridge recycling

You can help us raise funds simply by recycling your ink cartridges via our Recycle4Charity programme.

For each inkjet cartridge recycled via the programme we will receive up to £2, meaning you can help the environment whilst raising money for the CGF! You can get a free postage labels to send off your cartridges.

It’s a great way to involve workplaces too, encouraging companies to recycle their cartridges for the CGF. You can request a free box to collect cartridges. To start, all you need to do is go to this website to request your postage label or collection box: www.recycle4charity.co.uk/register/C93475

Leaving a legacy

Leaving a gift in your will can be done in a number of ways and will allow us to help more children, adults and families affected by growth conditions for the years ahead.

We strongly recommend getting a solicitor to draw up your will and you can find one in your area by visiting the Law Society: www.lawsociety.org.uk

Signing up to easyfundraising allows you to pick your chosen charity and we receive a % of every sale as you shop. Simply log into your easy fundraising account and go through the affiliated links: www.easyfundraising.org.uk
Join our new weekly lottery from £1 a week and be in with a chance to win £25,000!

The CGF Lottery costs £1 per entry, per week and enables us to raise much-needed funds to help support our charity. The draw is run every Friday and each entry has the chance to win one of four amazing prizes, including the top prize of £25,000!

You can enter online using Direct Debit or debit card payment or download a PDF form to print out and post with your cheque payment to Unity Lottery’s Freepost address. You can also use the PDF form to arrange a Direct Debit or debit card payment.

If you need help with joining our lottery please call Unity on 0370 050 9240. Find out more at www.childgrowthfoundation.org/weekly-lottery

We're registered with Making A Difference Cards, an online card platform where you can order individual printed cards, packs of cards and eCards too: https://gb.makingadifference.cards/supporting/child-growth-foundation

We're also registered with eCard platform Don't Send Me A Card, with e-Cards especially handy if you've missed the post cut off for a special date: www.dontsendmeacard.com/ecards/charities/child-growth-foundation

Both sites have a range of occasions including birthdays and lots of designs to choose from that you can add images and personalised wording to cards and support children, adults and families affected by growth conditions.
Take part in our...

EASTER VIRTUAL DUCK RACE

Prizes to be won
£2.50 per balloon
Eco friendly

Virtual ducks launch 2nd April at 12pm

Buy your duck before they launch at:

WWW.BALLOONRACE.NET/CGF
Great North Run

Ready to take on the world’s biggest half marathon?

New for 2023, the Child Growth Foundation have a limited number of places available in this year’s Great North Run, taking place on Sunday 10th September.

This is one the most popular running events in the sporting calendar, with runners travelling from across the UK and further afield to take on the city-to-sea 13.1-mile route from Newcastle city centre over the iconic Tyne Bridge to the coastal finish line at South Shields.

Places cost £64 each which covers your entry to the event, along with a free Child Growth Foundation running vest or t-shirt along with support from us in your training journey.

To secure your place, enter now at: [www.childgrowthfoundation.org/gnr](http://www.childgrowthfoundation.org/gnr)

If you’ve already signed up to the Great North ballot and secured your space, would you consider getting sponsored for CGF in your run? If so please contact us at fundraising@childgrowthfoundation.org and we can help you get started with your fundraising!

Fancy choosing your own fundraising activity? Jess and Hunter challenged themselves to undertake 47 miles of skating, walking and swimming to raise funds for CGF! [www.justgiving.com/page/jessica-watts-1672942945228](http://www.justgiving.com/page/jessica-watts-1672942945228)

The first 21 miles is the equivalent of the English Channel and the second 26 miles is the equivalent of following the Inca trail. If you’d like to chat about any ideas please let us know at fundraising@childgrowthfoundation.org.
Thank you so much to our members for continuing to pay the annual subscription.

The support you provide through both new or continued membership helps us deliver invaluable services to families affected by rare growth conditions. There are a number of ways you can pay for your membership:

**By Standing Order**
Account Name: Child Growth Foundation
Sort Code: 23 05 80
Account Number: 24218095

**By card**
Via our website: [www.childgrowthfoundation.org/membership](http://www.childgrowthfoundation.org/membership)

**By cheque**
Please make cheques payable to: Child Growth Foundation

**By Direct Debit**
You can set up a direct debit either by emailing laura.roy@childgrowthfoundation.org, by using the following link [https://bit.ly/cgfdirectdebit](https://bit.ly/cgfdirectdebit) or by scanning the QR code above.

If you have any queries regarding your membership please contact Laura at laura.roy@childgrowthfoundation.org.

Thank you to all our members!
Joining our membership

Become a member of

Child Growth Foundation

To help make a difference wherever growth is a concern

There are many benefits to becoming a CGF member, including:

- A printed copy of this twice-yearly newsletter delivered to your door
- Member-only benefits for our fantastic annual convention
- Access to our members-only area of our website

Along with these benefits to you, your membership payment will also be making a real contribution to our work to improve the lives of children, adults and families including our research, our range of information and resources, and our support line.

Membership costs just £25 a year to UK residents and £30 for those living overseas. The fee is the same for an individual or a whole family.

Find out more at: www.childgrowthfoundation.org/membership
Update on James

By James’ mum, Laura

Silver-Russell Syndrome

We have lots to tell you about since our last update, I’m not really sure where to start. James is now 14 years old and is in year 10, so lots going on at school for him as he continues to work towards his GCSEs. I am speaking with the SENCO about access arrangements for his exams, as it’s really important to get the additional support in place for him so that he can do his best in his GCSEs. We are discussing him having additional time, a scribe for the subjects that need precision and lots of writing, and breaks so that he can have snacks.

He has joined jazz band again and performed in Winchester Cathedral playing his guitar with the band. He was really pleased to get a small speaking part in the school production Bugsy Malone; he is going to rehearsals a couple of times a week and we are so proud of him for the commitment he is showing towards the play and all of his school work.

Unfortunately, the cholesteatoma has returned in his ear and he will be going to hospital to have another operation in early 2023. The ENT consultant will be doing a skin graft behind his ear drum to repair some damage and to reduce the likelihood of the cholesteatoma coming back, but we are really upset that James has to go through an operation again as it’s very painful and uncomfortable for him. He’ll need to have at least two weeks off school, so I am currently discussing the possibility of him having a home tutor with the SENCO so he doesn’t have lots to catch up on when he gets back to school.

In my last update I said that James has stopped having his prostap injections, which he was having 10-weekly to delay puberty. It’s now been a few months since he stopped and nature is taking its course. He saw his endocrinologist at the end of December and his linear growth has slowed up a little, which could be related to the peri-pubertal slow down in growth, so his growth hormone dose has been increased and we are very hopeful of seeing some significant growth. He is getting closer to my height now, so it won’t be long before he’s able to look me directly in the eyes!

He has now had braces fitted on his top teeth. He was showing a lot of concern about having them fitted, which he never does about his treatments or appointments, so I wanted to respect his feelings, and I was also concerned how he’s cope with eating and the impact it would have on his speech. I am really pleased to say that in usual James fashion, he took it all in his stride and didn't complain of it hurting or aching at all. He also realised that close family members and friends have braces, as well as people on the TV, so think he started to feel more comfortable and he was part of the trend! It all went so well, two appointments later he had braces fitted on his bottom teeth too, and despite a small part pingiing off when we were away over new year (when the orthodontist was closed), he’s had no problems at all and I actually think he’s pretty proud of himself and we’re proud of him too!
I’ve saved the biggest news to last. After lots of meetings and assessments with the psychologists in the Social Communications Disorders team at Great Ormond Street, James has finally received a formal Autism Spectrum Disorder (ASD) diagnosis. It feels bittersweet as we have seen ASD traits coming out much more strongly in the last few years so felt he had it, but at the same time, it’s still difficult to come to terms with the diagnosis and think about the impact it will have on his life.

The important thing for us is that he will now get more of the support he needs at school and, at the end of the day, he is still the James we know and love so much, so it doesn’t change much for us at home. Just lots more reading for us to do to now understand it and support him as much as we can.

Update on Robert

By Robert’s dad, Stephen

GHD

Welcome to my first report of 2023.

Things have moved on apace since my last report. Robert and Emily are now parents having welcomed William Alexander George to the family on 29th August 2022.

They are currently sharing parental leave, with Emily returning to work at the start of January and Robert now on leave until the end of March.

As expected William is being carefully monitored by the local hospital but there has been no indications so far that he has inherited GHD which is a massive relief.

House-wise, the nursery has been completed along with their bathroom but work has now slowed for some reason.

We visit as often as we can as William is our first grandchild and it is great to watch him grow. His christening is arranged for February at the village church and we are looking forward to catching up with both sides the extended family who live in different parts of the country.
Many of you probably know Daniel if you have come to the convention but we have never written an article as we were not 100% sure of his condition, but now we are so here goes...

Hopefully other families with the same diagnosis can get in touch and it would be good to meet up with them at the conference.

Daniel was very large when he was born – 11 lb 10 oz (5.28 kg) and was very long with a large head. (And yes I did give birth naturally!). His length and head size were off the growth charts – well over the 100th centile. He fed ok but was always dribbling.

He started to crawl like a commando but couldn’t sit up and didn’t walk till he was 3. He had speech therapy at school. He had joint hypermobility and hypotonia. He had heel cups for many years and needed to wear boots for support.

At about 8 months he wasn’t reaching his targets for sitting and, after seeing a paediatrician, he was given a clinical diagnosis of Sotos Syndrome due to his size, head size and floppiness.

When genetics progressed there was testing to see if the NSD1 gene was mutated or deleted to confirm a Sotos diagnosis. Daniel did not show this alteration in the gene. The geneticists at Guy’s Hospital kept searching and putting Daniel forward for different tests for other growth syndromes.

We always tried to attend the annual conferences to learn what we could and after meeting other families we could see that Daniel did not have similar facial characteristics to the other Sotos children. He was similar in other ways, with overgrowth, delays, learning disability, and increased head circumference.
When he was 14 he also got a diagnosis of autism which explained a lot of his behaviours. He had one-to-one support at a mainstream school and in year 4 juniors he changed to a special school that was better able to meet his needs.

He was always one of the tallest in his class at school but his growth slowed down and he is now the same height as his mum and dad (5ft 11). He has had several operations for gromits and t tubes and still attends ENT.

He has S-curve Scoliosis but as he has now reached his final height the doctors say it won’t change any more so he does not need an operation. He has pineal and arachnoid cysts on his brain and a hypertrohic kidney and cysts but as far as we know these don’t have an impact on him. His balance has always been poor and he wasn’t able to jump till he was about 15.

He is still unable to ride a bike. We tried him on an adult-sized trike but he found it difficult if there were any slopes. He still has difficulty walking up and down slopes and needs to hold on when going up and down stairs. He is not able to cross a road by himself - he has gaze aversion so doesn’t look properly and wouldn’t be able to judge speed and distances. It is hard work to get him to look at the camera.

We have difficulty getting horse-riding helmets and baseball caps. When he was younger he couldn’t go on so many things on days out as their hats wouldn’t fit him. Now we have found baseball caps from America that fit.

He can also be very anxious and this shows in his continuous repetitive questions. He likes his routines. He is scared of clowns, dogs barking and loud bangs and can get upset and angry if someone ignores him. However he also is very sociable and loves music, dancing, horse riding, Lego and food and gin.

Last year we were contacted by the geneticists with a diagnosis of Smith-Kingsmore Syndrome. This syndrome is very rare. There is a support group in America where they are funding research. The common features of this syndrome are developmental and intellectual disability, large brain size, seizures and autism spectrum disorder. SKS is caused by changes in the MTOR gene.

At the last conference, we managed to talk to Professor Kate Tatton-Brown who has been coming for many years to talk about Sotos, TBRS and other overgrowth conditions and are waiting for a referral to see her in her clinic to learn more about SKS.

We don’t really know what is next for Daniel. Now he is 24 and is in his last year at college. He also attends a day centre 2 days a week, which he loves, and gets to do many fun activities.

Unfortunately, due to Covid he wasn’t able to do any work experience. We would hope in the future he may be able to do a bit of volunteering work somewhere. He will never be able to live independently but we hope it may be possible that he can live in a supported living environment with other young people.
Recently my husband and I had the opportunity to attend the Child Growth Foundation convention with our 17-month-old daughter Freya.

We were taking her to meet her UK family after being cooped up in Australia during our Covid lockdown. It was absolutely amazing to meet families who have shared similar experiences to ours, and we made a bunch of new friends.

My husband did find it quite confronting though, when he realised just what Freya’s future might look like; he hadn’t done as much research on RSS as I had, and hadn’t realised quite how life-changing a diagnosis it can be.

My pregnancy was going well until week 28. During a routine growth scan the doctor became very alarmed when Freya suddenly dropped from the 10th percentile to the 3rd! We had a lots of scans in the hospital that day and shared a look of horror when the consultant “reassured us” that we wouldn’t need to have the baby taken out that day...

We made it to 37 weeks before Freya was born via caesarean at 2.2kg (4.8 lbs). Right from the start she had problems feeding, she had EBM with top-up formula and was just not gaining weight. However, after a week all alone in hospital with her during Perth’s only Covid lockdown I’d had enough and begged to be allowed home. She gained 30 grams the first day out, probably just being away from the stress. She continued to have very slow growth and was extremely unsettled – after 4 months she was switched to different formula as she was CMPI. Then she started actually sleeping a bit, hallelujah!

We visited the Child Health Nurse and emergency room so many times when she stopped feeding and got sick, and spent a fortune on hospital parking during her inpatient stays... it was a very stressful first year! Eventually we were seen by a lovely paediatrician at Perth Children’s Hospital, who asked if anyone had mentioned Russel-Silver Syndrome to us. When I Googled the list of symptoms we actually shed tears in the hotel cafeteria as we realised Freya had almost every single symptom!

Discovering that there was a reason she was failing to thrive, why she looked so different to other babies and why she was so late to crawl and walk was such a relief. Although it was tinged with fears for her future, which is why it was so important to meet other RSS families at the foundation.
Now Freya is 19 months and finally has her first few teeth. She’s almost running on her tiny feet! She is wearing age 9 months clothing and constantly surprising people with her cheeky attitude. We are still waiting to see if we get genetic confirmation of RSS and another condition called ectodermal dysplasia, but we know that while she may be small she is certainly a huge character who is going to leave her own mark on the world, no matter her size and appearance.

Our visit to the CGF convention really opened our eyes to the world of kids living with these growth conditions. We came armed with a huge list of questions, and got answers to everything. Growth hormones, genetic test, feeding, injections – there was someone there to talk about every aspect of Freya’s situation! We came away much better informed... and with yet another list of questions, this time for our doctors in Perth! Thanks to the conference we learned about a whole range of possibilities for Freya. Whilst her development may be slow and slight, her future will be full of love and support – and the best options our health service can provide.

David’s story

Sotos Syndrome

David Edgardo is a 12-year-old boy. He was born on July 21, 2010, at the Hospital del Maestro located in San Juan, Puerto Rico. Since his parents joined their lives, they always dreamed to have a son, a joy that was conceived with endless love.

David was born at 36 weeks by caesarean delivery due to a complication with mom’s blood pressure. Dad was able to be present during the birth process and mom was only able to see him for a few seconds, given his critical condition of not responding after his birth. David was transferred shortly after to a more specialized infant intensive care unit, while mom stayed at the birth hospital recovering from the surgery. At the new hospital, dad was the only person authorized to see David. Mom was able to be with the baby after she was released from the hospital. David responded to the treatment, showing signs of improvement, resulting in getting discharged after 7 days.

After his release, little David was received with all the love from family and friends. David has always been a happy child and noted wherever he goes. His physical development had some delay but thanks to his parents’ dedication he was able to receive the assistance and treatment needed. At his early stages he was required to use prescription glasses for strabismus. He also needed different types of therapies, to included physical, occupational, speech and language.

Although he had some delays in some stages of early development, his family and the therapists were always working as a united team and giving him all the required support to assist him on his development. At the age of one, David suffered a seizure due to high fevers, it was a terrifying experience, but thank God he was not affected.
Music makes him feel very happy; he likes to dance, play percussion, and make himself known and felt anywhere he goes. Once he began elementary school, other needs began to arise. As proactive parents, we requested more support from the school and from the therapist team to take care of David’s needs. This process included bringing on board new specialists to further assist him. Unfortunately, the public school system in Puerto Rico is not very inclusive and does not have all the resources needed by children with special needs. David was diagnosed with ADHD. The symptoms of this condition were notable in his daily life but never stopped him from smiling and enjoying every moment.

As parents, it was very hard and frustrating to have David attending an elementary school in an educational system that was not open to inclusion or providing the resources that he needed. As a result of the lack of resources, dad and mom made the hard decision to leave Puerto Rico and move to West Virginia. As a family, it was a hard decision as we were moving to an unknown area, with a language barrier, since the main language in Puerto Rico is Spanish. Furthermore, we left behind our families, friends and professional careers, but were happy because we were looking for new opportunities for our child and for a place where David was going to receive the academic support needed with quality services.

In August 2017, thanks to the support of his godparents who welcomed us into their home, we moved to West Virginia, full of dreams and looking for the opportunities to help and support David with his academic development in a suitable environment. The adaptation process was somewhat difficult due to the language barrier, but that did not stop him, David surprised us; he pushed forward and began learning the English language and making friends. At first, he had problems communicating but little by little everything began moving, and he became acclimated to the new challenge.

One day, using a drawing, he expressed that he was feeling sad because he wanted to be a normal child, meaning to be able to control himself and to be calm and not in constant movement, behavior that we as parents know is caused by his hyperactivity and impulsivity. That was the turning point for us as parents, so we decided to seek professional help from his pediatric doctor and start a prescribed drug treatment, something that we were opposed to at the beginning stages.

After we began the treatment, everything began improving with David; he became more focused and calmer. He was developing the English language, overcoming the barrier. He was also included in a regular classroom, with some accommodations through his Individualized Education Program.
After the paediatrician began working with him, David was referred to a psychiatrist to continue with the medication and to follow up this progress. David was also referred to a geneticist, who saw him and recommended genetic testing. Based on lab results, it was discovered that David has Sotos Syndrome. After 12 years we finally received a diagnosis that could help us getting the proper treatment and resources for our baby. Furthermore, now we knew why he faced the development struggles.

Thanks to early intervention, he has improved in many aspects and continues to show improvements. David has been in contact with numerous specialists, including geneticists, allergists, ophthalmologists, audiologists, neurologists, rheumatologists, speech and language pathologists, psychologists, neuropsychologists, among others. Whenever we had a doctor’s appointment, David would ask ‘Why do I have another appointment?’ so I would do my best to make it more interesting for him, I would tell him, because you are special, and they want to meet you.

David is currently in seventh grade, belongs to the school band, plays percussion, likes basketball, he had attended several camps, such as a basketball camps, summer camps. He likes to make new friends; his love for the music and dance has never changed. He is a loving, compassionate, empathetic teenager who likes helping others.

Our goal for us writing this story is for many parents to know and understand that as parents or caregivers we are very important in the lives of children, we can make the difference on their life. As parents or caregivers, we are the ones who know them, who can seek and get the help they need to fulfil their needs. Moreover, we need to be their voices and raise their concerns so they can be included and provided with the resources to feel better and overcome some of their struggles.

But above all, we are the ones responsible for providing them with all the love, patience, hope and motivation, so they understand that no matter how hard and difficult it gets to reach the goal, we will be there with them. Remember, it is not how fast we get there, it is enjoying the process with them and celebrating their achievement. We are certain that David will continue achieving goals with God’s help.

Share your story

You can share your story in a future newsletter, on our social media and/or on our website.

If you’d like to share your story with the Child Growth Foundation and the children, adults and families we support please get in touch with us at news@childgrowthfoundation.org.
Q&A with Rumeysa Gelgi

Guinness World Record holder Rumeysa talks with the Child Growth Foundation about her work to raise awareness of overgrowth condition Weaver Syndrome

How many Guinness World Records do you currently hold, and what are they?

Currently I hold 4 Guinness World Records titles: the tallest living woman, the largest hands (female), the longest fingers (female) and the longest back (female).

I’m also the former holder of the tallest living female teenager title.

Do you remember how old you were when you first understood you had Weaver Syndrome, and how you felt at the time?

I was around 5 or 6 I think. I have never felt bad or upset about it because my parents taught me that Weaver Syndrome (WS) is what makes me unique. I was amazed when I found out that I am the 27th person diagnosed in the entire world, and even I myself started researching to learn more at such a young age.

Given that Weaver Syndrome is so rare, do you feel an obligation to be a spokesperson for the condition? If so, do you see that as a burden or a benefit?

I didn’t feel that I’m obligated to, but I really wanted to do this. I always knew WS is quite rare and there are just a few people with it in the world. So I wanted to inform others and spread awareness. I’ve been voluntarily advocating for WS since I received my first ever Guinness World Records title 9 years ago and this gives me honor!

What sort of physical support and equipment do you rely on in everyday life?

I get around in a wheelchair most of the time and can walk with a walker for short distances.
You must get asked the same questions over and over again – what question are you most sick of answering?

As you know, one of the most common features of WS is a deep voice. Obviously I have that, too! However, many people can't figure out the reason and often ask me ‘What's wrong?’ with my voice!

In what ways did having Weaver Syndrome affect your teenage years?

In order to stop my overgrowth, I received a medical treatment from age 6 to age 9. The purpose of this treatment was to start my puberty via giving a high dose of estrogen into my body and then end it after enough time. So I was going to be able to reach my adult height as soon as possible and it would be the minimum. So, even though it sounds a little crazy, my puberty process started when I was 6 and ended when I was 9.

So as a result of this, in my teenage years, I already had an adult woman's body. I know this could be traumatic for a child at that age but my parents, who also have a medical background, did a great job of explaining the whole treatment and situation to me. So I never remember that I felt scared with what was happening.

What sort of impact has it had on your professional life?

I'm a web developer. I chose this profession not only because I have always been interested in computers and technology, but also as I thought that having a career in tech/programming would be the most suitable one for me since I have physical disability due to WS. I really wanted to follow a career path that I will be able to perform as a job and these type of fields have a lot of remote work opportunities, so I thought it would be a huge advantage.

Your long-haul flight to the US in 2022 required adjustments on the part of the airline to enable you to travel comfortably. Can you describe the experience of researching travel options and explaining your needs to the airline? Were they understanding?

I was born with scoliosis which is another feature of WS. Even though I was operated for that when I was 17 years old, I still have some curvature and carry 2 rods and 30 screws in my spine. That's way I can't sit longer than 2-3 hours at once and then I need to lie down and take a rest.

So my only option to be able to travel from Turkey to California in was flying on a stretcher.
Traveling on a stretcher is not a process that can be easily arranged. Usually it is used for passengers in a medical emergency situation. As far as I know this was the first time ever that this option was used for a tourist passenger.

So the entire process required a lot of research and preparations. I contacted Turkish Airlines, as it is one of the very few airlines that provide a stretcher option. In order to make this journey happen, they had to close six seats in the economy class of the plane and place a stretcher on them.

At some point in our discussion, this turned into a PR trip with Turkish Airlines. Everyone working there was super kind and helpful, and put my safety and comfort first.

How are you enjoying life in California? And what is your everyday working life like?

I'm definitely living my best life here. California, especially compared to where I live in Turkey, is way more accessible which is a huge benefit for me. I have been exploring Bay Area for the last 6 months, and recently spent a week in Los Angeles which was an experience I enjoyed a lot!

You have obviously faced a lot of obstacles and adversity in your life, how do you manage to stay positive?

I always had dreams and goals, and I knew that I can achieve them with hard work and dedication. Thanks to my family’s endless support, I have never let negative thoughts hold me back. Plus, being a 5 times Guinness World Records holder and a public figure are what keeps me motivated and going.
What advice would you give a young person coming to terms with living with Weaver Syndrome, or another overgrowth condition, such as Sotos Syndrome?

Your syndrome doesn’t define who you are as well as your talents. Always be aware of your potential, set goals for your future and do your best to achieve them.

What ambitions do you have for the future?

I have so many things planned to achieve in the future. In general I can say that I’m building a future for myself where I can live my life as independently as possible in the place I dream to live.

Is there anything else you’d like to share with members of the CGF?

Thank you for having me. It’s a privilege to share my story with you. I hope my story could inspire you and your children in one way or another. Keep fighting, being rare is precious!

Huge thanks to Rumeysa for taking part in our Q&A, and for helping to raise awareness of Weaver Syndrome.

To find out more about Weaver Syndrome and to access our support visit our website www.childgrowthfoundation.org/conditions/weaver-syndrome or contact our support line.

You can follow Rumeysa on her Instagram @rumeysagelgi.
Along with phone and email support we provide help and information to children, adults and families in many other ways.

We have a range of videos and presentations on our YouTube channel. In 2022 our videos on YouTube were watched by more than 2,900 people, with over 9,900 minutes of content viewed.

You can watch our videos on our channel www.youtube.com/@childgrowthfoundation

We have support groups on Facebook, including closed, condition-specific groups. You can find links to these at www.childgrowthfoundation.org/conditions

We also have our main Child Growth Foundation Facebook group: www.facebook.com/groups/cgfoundation
We are extremely grateful to everyone who has contributed to our newsletter and to all those who support our charity in so many different and valuable ways.

We are the leading UK charity focusing on the support, understanding and management of rare growth conditions to improve the lives of children, adults and families affected.

We make a difference wherever growth is a concern by:

- Supporting children, adults and families affected by rare growth conditions
- Funding research into greater understanding and management of these conditions
- Raising awareness and understanding of growth conditions, to improve their detection and support their earlier diagnosis
- Supporting health professionals in the optimal diagnosis and management of these conditions

Thank you so much to everyone who makes this possible.
Thanks so much for reading our newsletter. To close this edition, we wanted to share this beautiful poem from Sam in the CGF community. What a powerful poem, Sam!

Once I was a young boy who never grew

Once I was a young boy who never grew
I had tests from the hospital
I have had an injection which I have used 2089 times
Now I’m growing like everybody I know
If you see me with my friends
You’d barely know I have a condition
I’ve grown up with them
I know some of them could trick you

I play cricket with my mates and my brother
Even though we fall out with each other
We bat and bowl till times ends
Runs and wickets we love it together

I am strong cause of my injection
I feel pain when I have it but it is required
I’m glad I’m growing
It never makes me feel tired
At Edgbaston, we enjoy ourselves
We’ve grown more into Bear
We chant and chant COME ON YOU BEARS
My name is Sam; I am growth hormone deficient