Making a difference wherever growth is a concern
Thank you to everyone who has been involved in this edition of our newsletter and to you all for your support of our charity’s work.

We are extremely grateful, as always 💛

Disclaimer:

The Child Growth Foundation (CGF) has made every reasonable effort to ensure that the contents of this newsletter are accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of the CGF and no reference to any product or service is intended as a recommendation. Views and suggestions are those of individual contributors and are not necessarily endorsed by the CGF. Please consult your medical practitioner / healthcare professional for confirmation and/or advice.
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From our Chair

Once again, it was a pleasure to meet so many members and non-members, in October last year, during the CGF’s convention in Warwick.

As always, the convention was a fantastic opportunity to review and discuss the topics and issues that are important and relevant to families affected by growth conditions, and to meet and ask questions of the experts.

Also, based on attendees’ feedback, an expansion of the sessions to include, for example, guidance on to get the most out of physician consultations and a presentation and discussion on the emotional impact of growth conditions, was much appreciated.

We will include many other relevant and requested topics in future convention programmes and will always be pleased to receive your suggestions at convention@childgrowthfoundation.org.

I am pleased to confirm that planning for the CGF’s 2024 convention is well underway, and we look forward to seeing many of you in Warwick, in October, this year.

I am also pleased to confirm that two major CGF projects, discussed in the previous newsletter, are now close to roll-out: a CGF advertising campaign and a programme of GP education. The advertising campaign will target the public and is intended to encourage families to act upon any concerns they may have about their child’s growth.

The CGF expects that a school programme to educate school staff and nurses and a national drive to encourage and improve child measuring, planned for later in the year, will provide opportunities for raising awareness of, and providing justification for, families’ concerns.

The GP education programme will complement and bolster the community campaigns and aims to improve GP, and other first-line healthcare worker, knowledge and understanding of growth conditions, and inform them of how to respond more effectively to the expressed concerns of families about their child’s growth.
Convention attendee feedback on both projects was positive and has been invaluable to the completion and extension of key components; GP transition guidelines, for example, are now being developed for selected growth conditions.

We will keep everyone updated on the roll-out dates of both these key projects and hope they will soon start to drive the earlier detection and referral of growth conditions to the growth experts.

In addition to the above, the CGF will continue, in 2024, to strive to provide the best possible information, educational support and guidance for families affected by all the growth conditions the CGF supports. The CGF is currently investigating gaps in the support that was usually provided by pharma companies, for example, and is exploring opportunities to develop its own version of the support materials that have been shown to be most useful and needed.

The CGF is already developing a series of illustrated storybooks to portray the challenges of growth conditions and to encourage children to comply with their treatment. We will also continue to expand the CGF’s range of educational booklets and infographics, for example, for Sotos syndrome, and are developing a range of activities and opportunities to directly engage with yourselves: new e-mail ‘round-ups’, more virtual monthly chats, expansion of focus groups, and a pilot peer support group. In 2024, we hope it will also be possible to start the modernisation and expansion of the CGF website.

I hope you approve of the CGF’s immediate planned activities for 2024, which we will continue to develop and expand upon throughout the year. As always, we will welcome your feedback and suggestions, and will be grateful for any support that you can provide to enable the CGF to continue its support of families affected by a range of different growth conditions.

Many thanks and best wishes

Jeff Bolton

Notice of our Annual General Meeting

Join our Board of Trustees at our **AGM at 7pm (GMT) on Monday 14th October 2024** for important reflections and updates from the CGF as we report on the past year and look ahead to key our upcoming plans for our charity.

The AGM will be held on Zoom to maximise the opportunity for attendance across the UK and for our international members to be able to join too. Full members of the CGF have voting powers at this meeting, with Associate members and non-members also welcome to attend as observers.

To register to attend please contact info@childgrowthfoundation.org.
What an amazing few months it’s been since our last newsletter was published!

I attended my first convention in October and it was wonderful to meet so many families there, and to experience what a special event convention is. Thank you for making me so welcome. I came away from the event with a full heart and great pride to be part of the CGF team.

Lots of work goes in to the event behind the scenes, including by our staff, trustees, volunteers, guest speakers, the childcare team and entertainment providers, which is hugely appreciated. And we’re already working on exciting plans for convention 2024!

Our team had a busy November attending external events, representing the CGF and the conditions we support. We met and caught up with other charities, healthcare professionals and many other passionate people and organisations. A highlight for me was Beacon’s Rare Disease Showcase in London with some great talks and sessions, and great engagement with our CGF stand.

A key topic discussed at medical events we’ve attended is transition and the need for support, information and resources in this crucial area for young people transitioning to adult care. A number of our expert team of Medical Advisors are working with the CGF to develop transition resources, with Silver-Russell syndrome and Sotos syndrome transition resources coming soon.

We’ve got such exciting plans for the year ahead, with children and families at the heart of our plans. One example is our new Meet Ups - Laura and Jessica from our team are hosting Meet Up events across different locations and dates to bring familiar and new faces together for special days out. Keep an eye on our social media channels and our email updates for more details.

As we look forward I also wanted to take a moment of reflection to share a big thank you to Laura Cadd and Linda Washington, who have recently stepped down as trustees. We’re all so grateful for your time, passion and skills provided to the CGF, and the positive impact this has made.
It’s been a while since I wrote for the CGF newsletter. I always say writing isn’t my thing, but I want to tell you all about the new storybook *Your Height, My Height* written by yours truly!

The book was inspired by having a child myself who has Growth Hormone Deficiency, and always telling him that his height should not define him. I’ve heard him being called names, people think he is unable to do things other children of the same age can do and people not talking to him in an age-appropriate way, all due to his height. As a parent it’s heart breaking but I’ve always told him that his height should not hold him back from anything.

This book addresses that whether your small, tall or in-between, it shouldn’t hold you back. You can play with your friends, you can all achieve, you can all be nice to each other, and you can be friends together. I want this book to empower all children whatever height.

I have loved working on the book, and if it helps just one child, then it has all been worthwhile.

**Storybook inspiration**

For 2023 Anti-Bullying Week Laura shared a blog on our website showcasing some lovely storybooks that provide a unique and engaging way to address complex emotions and to empower children to understand and help manage their feelings.

Read the blog here: www.childgrowthfoundation.org/story-books-inspiration-anti-bullying-week

Buy *Your Height, My Height* here: www.childgrowthfoundation.org/yhmh
Update from Sally and Lisa, our nursing team

Convention

It was fantastic to see everyone at convention in October, Sally thoroughly enjoyed being part of the facilitated discussion sessions and we are very thankful to everyone who participated and shared their personal stories. It was of course Lisa’s first convention and she loved getting to meet and chat with people there.

We also introduced personal support slots on Sunday morning, providing a space for a confidential conversation and addressing specific queries.

While we had a positive response, some valuable feedback prompted us to expand our convention support options. At this year’s convention we plan to offer slots on both Saturday and Sunday, ensuring we are accessible to attendees throughout the weekend.

Virtual Cuppa and Chats

Reviewing and improving how we offer support is something we are constantly looking at and we were delighted to mark Children’s Growth Awareness Day in September by hosting a virtual cuppa and chat. It proved so beneficial that we have decided to continue offering virtual support group chats on a regular basis.

We are all aware of the value in being part of a community who have a shared understanding of the challenges and lived experiences of growth conditions, so this is a real opportunity to connect with other parents/carers and ask the CGF team any questions you may have. We may not always have all the answers, but we are dedicated to supporting you at every step of your journey.

SGA steering committee

We were approached by Sandoz to join their steering committee dedicated to supporting the early diagnosis and referral of children born SGA. Lisa joined their first meeting and further meetings are planned throughout the year.
Youth Ambassadors

Lisa is looking for volunteers to become Youth Ambassadors for the CGF. This opportunity is open to young people aged 16-25 years who have, or had, experience of a growth condition or concern.

Please contact support@childgrowthfoundation.org if you would like to have more information about on the role and Lisa will be in touch.

Kidscape

Sally wants to share information about the bullying prevention charity, Kidscape, who she had the pleasure in meeting at a Helplines partnership event.

Kidscape support children and their families across England and Wales to challenge bullying and to have happy, healthy relationships. Kidscape have a FREE ZAP workshop for children and young people aged 9-16 who have been impacted by a bullying situation.

For more information and resources please visit: www.kidscape.org.uk.

Thank you to our volunteers

Finally, Sally would like to say a huge thank you to Sarah Wheelhouse for all her hard work in bringing together our founding peer support group in Northern Ireland, who had their first meet up in January. Thank you Sarah! As always if anyone is keen to work with us and set up a support group locally, please don’t hesitate to get in touch at volunteer@childgrowthfoundation.org.

Sally and Lisa at the 50th meeting of the British Society for Paediatric Endocrinology and Diabetes (BSPED); a great three day event in Manchester.
We loved seeing so many of you at our convention! From those who joined the Saturday daytime sessions to those who made a weekend of it, thank you to you all for making it such a special event. Here’s a lovely selection of photos shared with us from over the weekend.
Convention returns this October!

We already can’t wait for convention to return Friday 25th-Sunday 27th October 2024 at Delta Hotels Warwick. Once again convention is open to both members and non-members of the charity, to reach as many people as possible through the event. As a thank you for your ongoing support, CGF members will receive a members goody bag!

Early bird booking will open for members in May on our website at www.childgrowthfoundation.org/convention and then open to non-members from June. An offline version of the form will be available on request at convention@childgrowthfoundation.org. As always, you can join us for the Saturday daytime where again we’ll be running childcare led by experienced providers you can book, or you can make a weekend of it and join our Friday and Saturday activities too.

Last year we had the theme of Halloween on the Saturday night and as the theme was so popular and as this year’s convention is being held over the last weekend of October, we’re excited to again have the theme of Halloween. Fancy dress is not compulsory but is very much welcomed for children and grown ups who want to join in the spooktacular fun. Donations of new, unopened raffle and tombola prizes would be very much appreciated!

Kate’s Bursary

We’re extremely grateful to the family of Kate who provide a bursary for a family to attend convention, in memory of Kate who enjoyed attending our annual event. Kate’s Bursary will be open for applications from May at www.childgrowthfoundation.org/kates-bursary.

Have your say!

We have our convention survey open to both those who DID and DIDN’T attend the 2023 event. All entries to the survey are anonymous and your feedback will be so helpful to our planning of our 2024 convention. Scan the QR code, right, to take the survey.
We’re delighted to have the following fifteen experts on our growing Medical Advisory Committee, providing expert guidance to the CGF team and getting involved in a range of projects with our charity to support children, young people and families, and also fellow healthcare professionals.

In the past year we are so pleased to have had three new Medical Advisors joining us; **GP Dr Fenella Johnstone**, **Clinical Psychologist Dr Nadia Sumers** and **Senior Nurse Ruth Wyllie**.
The Overgrowth Syndromes Alliance (OSA) has been recently formed, and we’re really pleased that Child Growth Foundation are involved in this international alliance.

The OSA developed a patient priority survey to gather the most important needs of their communities to share with researchers.

The data collected from the OSA Patient Priorities Survey was presented at the National Organization for Rare Disorders (NORD) Breakthrough Summit in Washington DC, October 15th-17th October 2023. Thank you for making your voices heard. You can view the 2023 NORD OSA Patient Priorities Poster by scanning the yellow QR code below (right).

This survey will be open indefinitely and the OSA will revisit the responses annually. To take part in the survey scan the blue QR code below (left).

The first Overgrowth Syndromes Alliance (OSA) Scientific Meeting is being held in early 2024. Patient priorities across Overgrowth-Intellectual Disability (OGID) syndromes (Malan, Tatton-Brown Rahman, Sotos, Weaver, PIK3CA and Smith-Kingsmore) will be shared at this meeting. Researchers, clinicians and industry partners, all with an interest in overgrowth, will be in attendance.

The goal of the OSA is to promote patient-centered research that is of the greatest benefit to the larger OGID community.
Parental experiences of the transition from paediatric to adult healthcare with their adolescent/young adult diagnosed with a Growth Hormone disorder: Research Summary

By Laura Foot

Previous research has primarily focused on patient and healthcare provider experiences, failing to consider parents as key stakeholders. However, according to healthcare transition research, parents are potentially a key factor in transitional success. This study applied thematic analysis to investigate how parents of adolescents and young adults (AYAs) with GH disorders experienced the transition from paediatric to adult healthcare.

Five UK-based parents were recruited from the Child Growth Foundation support group and interviewed online. Analysis of the interviews identified three core themes. These were: “Support mechanisms”, “Balancing parental responsibility”, and “Recognising and reacting to change in the young adult”. The study confirmed inconsistent transitions despite best practice guidelines, which had a significant impact on the parental experience.

Conclusion

The present study contributes towards understanding the parental experience of the transition to adult healthcare with AYAs with GH disorders. Recently, studies have focussed on transition best practices, and separately, on the introduction of new technology to aid medication adherence. In this regard, the current study is an important and timely contribution to this field of research, supporting the suggestion that a well-planned and well-executed transition that is patient-centred and involves parents will result in better outcomes. Moreover, acknowledgement of parents as key contributors will further enhance the transition experience and thus improve clinical results.

The present findings suggest possible implications for clinical guidelines: in particular, they advocate best practices for reviewing the choice of device to ensure that it is fit for purpose for the AYA and providing a transition programme specifically for parents which includes coping skills and defined roles and helps with secure attachment to enable them to adequately support their AYAs, resulting in an improved experience.

For the full paper, please contact: stu96284@ardenuniversity.ac.uk.
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 catriona@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.
The GenROC (Genetic Rare conditions Observational Cohort) study has now been open for 9 months and is open at 21 NHS sites across the UK. 117 families have all of their initial questionnaires completed and another 100 are in the early stages of joining the study. However, that means they still have lots of spaces available for more families to join as they are aiming for a total of 500.

One of the specific aims in the study is to better understand the growth and development of children with these rare conditions and they are particularly looking at some new methods to devise growth curves that are specific to the genetic condition. This will be really helpful for families and doctors.

To be eligible you need to live in the UK, your child needs to be under 16 and your child needs to have an eligible genetic condition (and can only have one genetic condition). The list of conditions can be easily searched by scanning the QR code below:

![QR Code](image1.png)

To enrol go to https://redcap.link/GENROC or scan the QR code below:

![QR Code](image2.png)

The GenROC team have a web page www.bristol.ac.uk/academic-child-health/research/research/genetics/genroc-study. They are also on Facebook at www.facebook.com/genrocstudy or you can email them at genroc-study@bristol.ac.uk.
We’ve previously shared the Cerebra Network’s Behavioural and Emotional Outcomes in Neurodevelopmental Disorders (BEOND) study.

The Cerebra Network have asked the CGF to pass on their thanks to our newsletter readers and anyone in our community who has participated in the study. They really appreciate people taking the time to share their views and experiences for such an important study. For anyone who did complete the study you can also expect a feedback report outlining the results for the child they care for from the BEOND study team.

A message from Same But Different

Same but Different has been actively engaging with individuals and organisations over the past few months to shed light on the impact of rising living costs and gather insights into how lives are being affected. Through this process, we gained an understanding of the challenges faced by our communities and the subsequent support they require. As the cost of living continues to rise, we must stand together to support those most affected.

In our comprehensive web guide, we offer over 300 sources of assistance, all under easy to navigate headings. Together, let us extend a helping hand to those who need it most and make a positive difference in the face of the cost of living crisis please share and help those that need it. Visit our website: www.samebutdifferentcic.org.uk/costofliving

Finding help just got easier

A resource for families affected by rare disease and disabilities

www.samebutdifferentcic.org.uk/costofliving

Supported by:
Max Lymbery raised over £1,500 in his Land’s End to John O’Groats cycle ride.

Supporter Sarah (who’s two children are pictured above) nominated us with her employer, Volkswagen Group UK Ltd, who donated £2,000.

The Site Negotiation and Legal team within Cellnex UK raised over £1,000 walking, running, cycling and swimming the distance from Land’s End to John O’Groats throughout the month of July.
January challenge success

As we headed in to the new year we invited our supporters to take on a January wellbeing walking challenge and we’re delighted that over £800 was raised for the CGF!

Huge thanks to everyone who took part.

Jenson took part in our challenge, raising £265! We had these lovely photos shared with us from his wintery walks.

Claire, Darren, Albie and Laurie raised £370 in the challenge and shared these great photos taken during their fundraising walks.
Hey everyone,

I'm Georgia Bell, and I'm thrilled to share my journey with you as I gear up for the 2024 London Marathon. But this isn't just about a personal challenge or crossing the finish line - it's about running for a cause very close to my heart, the Child Growth Foundation (CGF).

Let me start by telling you a bit about myself. I live with Turner Syndrome, a condition I was diagnosed with at birth that affects around 1 in 2,000 baby girls and women.

It's a genetic disorder where one of the X chromosomes is partially or completely missing. This condition can lead to a range of health issues, from short stature and heart problems to difficulties with learning and fertility.

After going up to London to watch and support a friend run the marathon in 2023 I couldn’t help but be inspired. The atmosphere was electric, the very next day I decided to look into entering via the ballot and thought what the hell I’ll put my name in the hat. Not expecting to actually get it! When I secured my spot in the London Marathon through the ballot, I was both petrified and ecstatic.

Running the marathon has always been something on my pre 30 bucket list and at 27 it was nearing close, but with Turner Syndrome impacting my life, I realised there was a unique opportunity here - to raise awareness and funds for the incredible work CGF does to support individuals like me.

So, why CGF? Because they’ve been a beacon of support, providing invaluable resources and guidance to individuals and families affected by growth disorders like Turner Syndrome. From access to medical information to emotional support, CGF plays a pivotal role in improving the lives of those navigating these conditions.
The journey toward the marathon has been incredible so far and although at times it’s been tough I’ve surprised myself at what I am capable of. The support and generosity I’ve received have been overwhelming. I’m thrilled to announce that, thanks to the kindness of friends, family, and supporters, we’ve already raised an amazing £586! Every penny goes directly to CGF and will make a real difference in the lives of those who rely on their services.

Training for a marathon is no easy feat. It requires dedication, persistence, and a lot of running shoes! But knowing that I’m not just running for myself, but for a cause that means so much more, keeps me motivated every step of the way. So, here’s where you come in. Your support means the world to me and to CGF. Whether it’s a donation, spreading the word, or simply cheering me on from the sidelines (virtually or in person), your encouragement fuels this journey.

As I prepare to tackle those 26.2 miles through the iconic streets of London, I invite you to join me in making a difference. Let’s turn every stride into a step towards raising awareness, supporting those affected by growth disorders, and showing the world the strength and resilience of our community. You best believe that when I’m struggling during the race I’ll be thinking of everyone CGF positively impacts to get me to the finish line!

Thank you for being a part of this incredible journey. Together, we can make a meaningful impact.

You can sponsor me here: 2024tcslondonmarathon.enthuse.com/pf/georgia-bell

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**Caroline’s Cardiff Half Marathon support**

Supporter Caroline Buffett is taking on the Principality Cardiff Half Marathon in October for the CGF, inspired by her son Evan (pictured here with his sister Elena).

Caroline, who has already raised over £300 towards her £1000 target, shared her moving story about her son Evan and her inspiration for supporting our charity on her JustGiving page at [www.justgiving.com/page/caroline-allen-1705063596871](http://www.justgiving.com/page/caroline-allen-1705063596871)

“As we start our journey giving daily injections of growth hormone treatment to Evan, I am beginning another journey of running. Most of you will know I’m not a runner, having only run to catch trains, buses etc in the past. But I want to thank the Child Growth Foundation for the support they’ve given me and support their work further by raising awareness of this rare, invisible but very real disorder.”
Family and friends were shocked and saddened at the sudden and unexpected death of Annette Heslam on Tuesday 19th December, 2023. Annette died at home in Foxton, Cambridgeshire at the age of 67.

A Registered Nurse by profession, and ultimately a Health and Social Care Lecturer, Annette became connected with the Child Growth Foundation in the months after the birth of her first child Katherine in early 1982.

Annette’s baby was diagnosed early in pregnancy, as “Small for Dates”, and after close medical monitoring month by month, Katherine was born by Caesarean Section with Annette just 32 weeks into her pregnancy.

Tiny baby Katherine weighed just 2lbs 6oz (1.08Kg) and though perfectly formed and fully alert, she measured barely 1ft in length!

Annette and husband John spent over 7 weeks visiting Katherine daily in Paediatric ITU at her Cambridge Maternity Hospital, before she was eventually allowed home weighing just 4lbs!

Two further pregnancies in the next four years saw Annette yield full term, average birth weight, and average size children. Through concern for Katherine’s ongoing small stature, Annette became aware of the activities of the Child Growth Foundation, primarily driven and managed in those days by founders Tam and Vrely Fry.

Tam and Vrely proved a fount of knowledge, help, experience and reassurance to the Heslam family, and also introduced them to the growth orientated research, and medical expertise, of a then young Dr Richard Stanhope, now a famed Endocrinologist of over 40 years standing.

Katherine lived a normal life at home and school, albeit comfortably always the smallest in her class! Treatments for Katherine then extended to use of the then new and radical “Synthetic Growth Hormone” injections. Annette undertook Specialist Nurse Training with pharmaceutical pioneer Serono, and thus taught other parents and children how to master Injection Techniques for the daily doses of Growth Hormone needing to be administered at home.

These eventually extended to many 8/9 year olds “self-administering” their own injections, at which still small Katherine was brave, adept, and happily mastered the technique required.

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Tribute to Annette Heslam: Early Years Member of CGF

By her husband John
Annette and John attended several of the very early CGF annual conventions at which the aforementioned Richard Stanhope and others were Keynote Speakers. Parents and children enjoyed these CGF conventions that combined information sharing and parental interaction with meals together, music sessions, and fun events for the children and families.

In her later years Annette achieved a Degree Level Qualification and focussed on Nurse and Healthcare Staff Teaching and Assessing, where she derived great satisfaction from assisting many young people achieving qualifications to progress their careers in the Healthcare Profession. She was still working in this field, and also still nursing, when she sadly and suddenly passed away.

Katherine meanwhile had grown into adulthood, albeit at a modest 4ft6ins height, married husband Tim, and brought two full term conventional sized children into the world. Katherine has continued to retain connections with the CGF throughout her own life, and has herself attended, and contributed to, several CGF annual conventions.

Over 120 friends and family attended Annette’s recent Funeral Service. The Child Growth Foundation was nominated as Annette’s favoured charity in lieu of funeral flowers, and over £1,600 was raised for the CGF as memorial donations in Annette’s memory.

Annette leaves grieving husband John, children Katherine, James, Amanda and William, and seven grandchildren.

The Child Growth Foundation team were very saddened to hear of Annette’s unexpected death.

We’re extremely grateful to Annette’s husband John for sharing this beatiful tribute, and to John, their children and grandchildren for this wonderful support in Annette’s memory for our charity and the children and families we support.
Earlier in this newsletter (page 7) we shared the news about our upcoming storybook; **Your Height, My Height**. We’re really pleased that we’ll be expanding this range of books, including a Sotos storybook in development, and we’re now fundraising to produce a Silver-Russell syndrome storybook too, aimed at children and families who have a Silver-Russell syndrome diagnosis.


We’re also expanding our range of e-cards, featuring beautiful designs by a talented supporter. Visit [www.childgrowthfoundation/ecards](http://www.childgrowthfoundation/ecards) to see the range and support the CGF with this environmentally friendly alternative and donate the cost of cards and stamps instead!
**Becoming a member**

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

- A printed copy of this bi-annual newsletter delivered to your door
- Member-only benefits for convention including early bird booking and member goody bag
- Access to the members-only area of our website
- Voting powers at our AGM

Along with these benefits to you, your membership payment will also be making a real and lasting contribution to our work and the children and families we support.

Membership costs £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

**Renewing membership**

Thank you so much to our members for continuing to pay the annual subscription.

This support you provide through both new or continued membership helps us deliver our range of services to families affected by rare growth conditions and those seeking a diagnosis.

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

**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 bit.ly/cgfdirectdebit or by scanning the QR code above.

For any queries regarding membership please contact laura.roy@childgrowthfoundation.org.
Our Support Line

Our 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.

**How to contact our Support Line**

Email us at support@childgrowthfoundation.org | Call us on 020 8995 0257 | Complete our Support Line contact form at www.childgrowthfoundation.org/supportline.

**Support Line Privacy Statement**

By contacting the Child Growth Foundation Support Line you are providing consent for us to collect, process and store your data to provide you with the information or services you are contacting us about.

To read our full Support Line Privacy Statement visit: www.childgrowthfoundation.org/supportlineprivacy.

**The impact of our Support Line**

Our Support Line is led by our nursing team Sally and Lisa, who provide this supportive, safe and informative service.

It is thanks to funding and fundraising received for the Child Growth Foundation that we are able to continue this vital service.

In 2023, Sally and Lisa hosted over 110 calls and 290 emails to those seeking support on a range of issues around child growth.

The dedicated team spent over 108 hours, equating to 6,484 minutes, delivering our Support Line over the last year. An incredible support system which we’re so grateful to our supporters and donors for making possible.

To help continue our work please consider making a donation at www.childgrowthfoundation.org/donate.

A £9 donation to our charity could fund a 30 minute Support Line call with our nursing team for families concerned about their child’s growth.
Help us make a difference wherever growth is a concern

Fundraise  Volunteer  Donate

To find out more and get involved:
Email info@childgrowthfoundation.org
Call us on 020 8798 2139
Visit childgrowthfoundation.org
Or scan the QR code
Our latest infographics

Top tips: mental health and wellbeing
For parents, by parents

Talk to people willing to listen. Don't be afraid you're oversharing and don't keep what's troubling you to yourself.

Find other medical/growth community parents. Share your stories and listen to theirs. Remember that your child is unique but you're not alone.

You're not alone. The first couple of years are the hardest. Things do get easier. Remember that your child wouldn't be doing as well as they are doing if it wasn't for you! Be proud.

Comparison is the thief of joy. Celebrate your own child's success and milestones rather then comparing them to those of a typical growing child. Your child is working so hard, find peace in that.

Find your community, you don't have to be alone in this.

Find other parents through support groups that are going through the same thing so you don't feel so alone!

On difficult days try to find someone to talk with friends, family or other parents through the CGF who can listen and support.

Access any support you can. Don't feel guilty about finding your child difficult to 'like' - it can be very hard sometimes. Don't neglect your mental health - counselling is really worth it.

Reach out, make sure you have a solid support network and don't feel bad about prioritising yourself. Without your own health, you can't be there for others.

Practice self care!
Measuring at home

Measuring your child at home helps to identify any health or growth concerns.

You should measure both their height and their weight. Some tips on measuring both of these at home can be found at [https://childgrowthfoundation.org/wp-content/uploads/2020/03/ParentGuide_v1.0.pdf](https://childgrowthfoundation.org/wp-content/uploads/2020/03/ParentGuide_v1.0.pdf) (page 8-9)

The height should be measured in cms and the weight in kgs.

What to do with the information?

You should keep a note of the measurements you have and the date they were taken so that you can see how much your child is growing over time. The information can be plotted on a growth chart which will show you what centile your child is on.


Does family height affect your child’s growth?

Parents’ height is one of the important factors when considering how a child is growing. A mid-parental height is calculated to help assess whether your child is growing as would be expected for your family size. You can input your information into an online calculator such as the one found at [https://morethanheight.com/en/calculator-charts](https://morethanheight.com/en/calculator-charts) to tell you what your family mid-parental height is. If you’re still not sure please contact us at the Child Growth Foundation.

How often should I measure my child?

We would recommend that you leave at least 6 months between measurements so you can build a picture of how your child is growing.

It’s not always just about how much they are growing, but also the rate at which they are growing.

What do I do if I’m worried or have more questions about my child’s growth?

Please speak to your GP about your concerns or you can contact our Support Line via email at support@childgrowthfoundation.org or by phone on 020 8996 0257.
Q&A with Gracie Taylor

Silver-Russell syndrome

Gracie is living with Silver-Russell syndrome (SRS) and is currently in her final year of a Biomedical Sciences degree, specialising in Pharmacology at UCL.

Hi Gracie!

Q: When were you first diagnosed with SRS? What was the process like? What help and resources were available to your family at the time?

A: My family had somewhat of a working diagnosis from when I was around 6 months old all the way until I was 2. The process went from a clinical geneticist noticing some distinctive physical characteristics when I was a baby that then prompted a range of genetic tests to confirm their hypotheses.

Initially my family were offered access to the clinical genetics team in Edinburgh with any questions they may have. The charity was mentioned but due to such an large amount of new information upon my diagnosis this felt overwhelming and ultimately wasn’t something my family chose to access the support of.

Q: In what ways has SRS influenced your choice of subject and the direction of your studies?

A: I remember from a young age I was absolutely fascinated by the human body, as I got older and started to choose my subjects for my exams in secondary school I was focused on trying to get into medical school. This was definitely motivated by my experience as a patient. I knew if I was going to be a doctor I wanted to work in paediatrics to offer support and reassurance to other children having to spend a lot of time at hospital appointments like I had.

Eventually I realised that a career in medicine didn’t actually align with my interests, I was far more stimulated by the idea of learning about the theory of human biology and how all of the areas of study within medical science interact (genetics, pharmacology, neuroscience etc) so based on this I decided to apply to study Biomedical Sciences at university. I would say that SRS definitely provided the initial inspiration for where my future career could lead and I very much use it as my drive to make a difference in finding solutions for patients.
Q: What ambitions do you have for when you graduate?

A: I have always been very career driven so my main focus is looking for graduate roles, hopefully within the pharmaceutical or biotechnology sector however, I am definitely open to pursuing some of my current academic interests at a postgraduate level. Recently I’ve tried to focus more on key attributes I want in my career as opposed to landing on a specific ‘dream job’ job title. I know that I will find the most fulfillment in a career that places high importance on connecting with and educating people.

One of the motivations that SRS has given from me from a career point of view is a desire to make a difference in some shape or form and prove to both myself and potentially others that a diagnosis doesn’t necessarily limit your potential to achieve.

Q: What sorts of challenges does living with SRS bring to your day-to-day student life?

A: University life is hectic and particularly in London where the student and young professional cultures do blend into one another, I can find myself suffering with chronic fatigue fairly often. I feel particularly lucky living in London that the public transport options are vast so as a city it is very accessible and I rarely find myself having to walk too far. I live a very independent life and now being in my final year I have a really established support system around me at university. My biggest thing that I find myself having to manage is not always being able to predict when my chronic fatigue is going to hit me, I have numerous adjustments in place with the university wellbeing service that ensure this doesn’t put me at any disadvantage however, I definitely feel frustrated sometimes that I can’t do as much or I need to take a rest day. I try my best to check in with myself and how I’m feeling and then try to plan my weeks flexibly.

Q: Do you remember how old you were when you first understood you were affected by SRS? What was that experience like? Did you have a sense that you were different to your peers?

A: I think I always had an awareness that I was a bit shorter than my friends and had to go into hospital fairly regularly and they didn’t have to. I’m not sure on the exact age I would have been but my earliest memory where I remember feeling different was when I was in primary school, probably aged 5/6.

In my first year of primary school, as a class bonding activity we were asked to stick a coloured strip with our name drawn on to the classroom wall at our height. I vividly remember stepping back and realizing how far below my peer’s my sticker was. I don’t remember exactly what my initial emotions were but that was definitely the first experience that I can remember feeling different to my peers. As I’ve gotten older that sense of feeling different definitely sticks with me and is something I have to work through in my head when I’m in a new environment.
Q: Have you encountered many misconceptions about SRS in the general public? If there was one thing you wish everyone could understand about the condition, what would it be?

A: I think there are quite a few misconceptions following someone from the general public’s initial impression of me however, it’s hard to identify misconceptions about SRS due to the condition being so rare and most member of the general public wouldn’t have heard of it. When I was younger, due to being smaller most people definitely assumed I was younger than I was, as I’ve gotten older and facially matured this happens a lot less. However, I find that people do stare sometimes in public but it’s something you get used to.

I would say I have a few main things I wish people knew and are often the first things I tell people as they get to know me: one is the fact that my height really isn’t the aspect of my condition that impacts me the most. Yes I do get a few stares, find it difficult to reach things but the thing I struggle with the most is my chronic fatigue. Another massive point is that people do like to put me under the ‘dwarfism’ umbrella term, which absolutely in the right context is correct due to me being short in stature, however I do think many people expect me to have had the same experiences as someone with achondroplasia, a form of dwarfism with far more public representation and for the most part this simply isn’t the case. Finally, I genuinely don’t mind being asked a question about my condition if it comes from a place of genuine curiosity and is in an appropriate situation. In my experience giving people a little bit more knowledge is only a positive thing!

Q: One of the things that can come with living with a rare condition is feeling as though you are expected to publicly ‘represent’ it. Is this something you find frustrating, or do you enjoy the opportunity to educate people (or both!)?

A: I’ve personally never found this frustrating, in fact I feel extremely grateful to be in the position and comfortable enough with myself and my condition to share my experiences. By talking about my experience in the context of offering advice it gives me a perspective that allows me to process some of my thoughts and feelings about my experiences in a more neutral way. I find being able to share my stories, hopefully offer some support to individuals affected by the condition and also educate those who aren’t as familiar with SRS to be incredibly cathartic.

I think we often talk about representation on a larger scale like in the media or within large corporations however, very rarely is it discussed on a more personal level. The idea of walking into a room and feeling like nobody looks the same as you is an important one to address when talking about representation. On a personal level, sometimes I can really get in my own head about this but more often than not I use it as my motivation to go to events as I always think maybe I’ll make someone else in the room feel more comfortable to be there.

I would absolutely love to see more people who look like me on adverts and in films but smaller scale representation is far more important for giving people the confidence to enjoy their everyday lives.
Q: How did you first come to be aware of the CGF? From your perspective, what do you think is the most valuable aspect of the charity’s work? Are there any areas on which you think the CGF should focus more?

A: I personally first became aware of the charity when I was involved in an event with the University of Edinburgh’s Institute of Genetics and Cancer titled ‘Shining A Light on Silver-Russell Syndrome.’ Myself and my clinical geneticist Professor Mary Porteous delivered a Q&A with one another and then representatives from the CGF (Chair of Trustees Jeff Bolton and Medical Advisor Dr Emma Wakeling) shared some of the charity’s work with the audience.

I would say the most impactful work the charity does is creating a space where families can access support and ask questions that has a community and more relaxed feel to it. Currently the charity really does go above and beyond for families and patients with growth conditions however, the main thing I think would be great is if there was a way they could offer a platform in which young people could talk to each other more informally. I know this isn’t for everyone and I think even I would have been nervous to talk about how I felt with someone I didn’t know, however many young people often feel more comfortable talking to someone they don’t know as well.

Q: What piece of advice guidance would you give to a young person living with SRS? And what would you say to the parents of a child in the process of being diagnosed?

A: There are so many pieces of advice or even just reassurance I feel I could give particularly when I think of my younger self so I’ve narrowed it down to 3:

1. It’s okay to be frustrated and wonder if it would be easier to not have SRS but don’t dwell on it and give yourself a hard time for something you can’t control. The reality is that most people have something going on, I really try my best to focus on the things that SRS makes me appreciate.

2. Make sure you stay in touch with how you’re feeling, whether you like to write your thoughts down, talk to a close friend or just take a moment to reflect every so often it’s really important especially as you move through the big milestones of young adulthood.

3. This last piece of advice is particularly directed to my younger self; please don’t be afraid to take up space just because you don’t see anyone who looks like you doing the same. If you have something you want to achieve, you are more than capable and deserving of the opportunity to chase after that.

In terms of advice I could give to parents of a child, I asked my mum what she thought and from everything she suggested this was the piece of advice she would give that resonated most with me. It’s really important, particularly in the early days, to take everything one day at a time as it will feel like a lot of information to take in. You need to recognise that it is a life changing diagnosis for the whole family/your child’s support network and it will affect everyone in different ways. Focus on the positives of what your child CAN do and try to give them enough confidence to go out into the world. Make sure as much as you can to equip them with the tools to cope with the challenges of the world, as young people they have a world of potential to fulfill that shouldn’t be limited by such a diagnosis.
Q&A with Elizabeth Wills

Sotos syndrome

Elizabeth Wills is 29 years old and has Sotos syndrome. She lives in Southsea, Portsmouth with her mum Lisa.

Hi Elizabeth!

Q: When were you diagnosed with Sotos syndrome?

A: I was diagnosed with Sotos syndrome when I was eight years old we got the diagnosis from two paediatric physicians. Dr Karen Temple and Dr Joe Walker were the two paediatric physicians who gave the initial diagnosis, and Dr Thomas from QA hospital was the one who worked closely with us on my ears.

Q: What is your earliest childhood memory?

A: My earliest childhood memory was just before I had my heart operation I remember being wheeled into the theatre and I had strawberry gas to put me to sleep, and on the walls were an underwater scene and as a momento from the operation, the doctors gave me a dolphin stuffed animal, and it is still on my shelf to this day.

Q: Did you enjoy school and college?

A: I really enjoyed my time in education. The only thing I didn’t enjoy was the bullying that started in Year Eight which took the form of students hitting me on the forehead and shouting spam!

Q: What was school and college like?

A: For the most part it was awesome actually, I met my best friends and I really excelled in art and design textiles and child development. I wasn’t so skilled in the more academic studies, such as maths, science and history and english. I got good grades in them though, they were not the topics I was particularly gifted in.

Socially school and college weren’t that enjoyable because of certain mental health problems that nearly all teenagers at that age go through. Mine was for me was intense but I don’t regret it, though it made me the person who I am today. I don’t regret anything because it taught me resilience, and a chance to figure out who I was as a person which is very thoughtful, punctual and forgiving person.
Q: Did you have lots of hospital appointments as a child?

A: I remember going to the physician a lot because I was over developed in some areas but under developed in others. So for instance, the rate in which I was growing was quicker than my peers but my hearing and my speech were delayed, so when I finally did speak I sounded like a deaf child. I remember Mum saying to me once that somebody had once said to her, is your child deaf?

There were also a lot of visits to the ENT department as well because my nose to my ears blocked up really easily, and so I have to have this thing called micro suctioning every three months. It's been a battle to get the every three months, but we got there and I have been having them every every three months since.

Q: What happened when you left school?

A: After I left school I went on to do a year of Art and Design at level two which was very enjoyable. But I knew that my calling as it were lay in helping people, after visiting the home that my granddad was in. I knew that that was all I wanted to do was to help either elderly people or young people. That being said, I applied that summer for health and social care. I did that for two years and then because I loved it so much I went onto do a further two years of social care which is how I ended up where I am.

But before that straight after I left after I left college I went onto do a apprenticeship in childcare, which went really well, resulting in one of my answers is being used as an example for one of the questions on the apprenticeship itself for future students.

Q: What do you find most challenging about having Sotos?

A: The thing I found most challenging about Sotos syndrome is the physical side of it because now I'm getting older I am finding that I’m getting creakier, so my joints and my skeletal system are getting a little bit achy. But in order to help with achiness, I take baths and I have heat rub cream to help with inflammation.

The other challenge is memory, but I am able to find certain strategies in order to prevent that from deteriorating anymore than it has already. So for instance, when I’m doing a job at work I will collect things on a list and I will tick off the bits that I have, and then I will look at the list again to make sure that I’ve got everything back in the box I need to. The other things are dates as well, but there again I have found ways to constantly remind myself about where I’m supposed to be on what particular day.

Q: What are your plans for the future?

A: I have a job with the play service which is run by the local Portsmouth city council. My plans for the future is to become a play worker because I’m in training now and I absolutely love it!!!!
Update on James
By James’ mum, Laura

Silver-Russell syndrome

The end (as we know it) is in sight!

James has made it to his final year at secondary school! In our last update I wrote about James finishing his first round of mocks – since then he’s had another round, has a final few at the end of January and his GCSEs then start from mid-May. He’s struggled most with having to do more work at home, as like many children with ASD, school is where he does his school work and home is home.

Revision has been a struggle as it’s overwhelming and difficult to process for him (and us!). As much as possible he’s attending school revisions sessions and we’ve created a timetable for home, so he gets in a routine and knows the plan. Overall this is working well (apart from his literal approach to timings – so if we’ve set an hour for a subject and he reaches the hour he will stop whether he’s in the middle of something or not). He also likes to put his headphones on and watch things on YouTube, so I’m going to look into BBC Bitesize and other video options to aid his learning and revision.

The next big step is then college. It’s fair to say I can’t have ever imagined him doing so well and getting this far when he was a tiny baby in SCBU and the smallest child in primary school who could only just walk, didn’t eat, was on numerous medications and could only say a handful of words. We didn’t really know where to start when looking at colleges and we’re still exploring options, but since September we’ve managed to drill down on James’ interests and what he enjoys the most and then explored which colleges offered the right subjects and level of courses. He won’t be doing three straight A-levels but potentially a mix of BTEC, diploma and an A-level. On top of the open evenings (some of which we’ve attended more than once), we’ve also booked a time to meet with the learning support/student support teams at the college and have a one to one tour. That’s helped to get a better feel for the college and if he has a good learning culture that embraces children with EHCPs. We’re going to apply for his top few and then make a final decision in the next month.

To add to an already demanding time, we discovered our local authority had let James’ EHCP get incredibly out of date. We’d been having annual reviews at school and updates has been sent but the caseworker had not been adding the updates – so it still had lots of references to his primary school needs and his medical needs and educational needs have of course changed considerably since then. He’s been having TA support at school and the SENCO went on and arranged for an ASD specialist SALT in to assess James, even with his EHCP out of date. The assessments by this specialist have been invaluable and her findings have now been added to his EHCP.
Even after all this time (James has had an EHCP since his first year at primary), the process is still confusing and complicated (the cynic I me says it’s on purpose) and the lack of local authority support is shocking.

I am, however, pleased to say that this week I’ve received an updated plan for review, so all of my phone calls and emails have started to pay off and I’ll be reviewing the updated plan this week.

We’ve settled into having a new GHT device and getting used to Gentrophin, but if we had the choice, we’d have rather stayed with Norditrophin as it was easier to use in many ways. James had his six-monthly appointment with his endocrinologist in October and he’s shown good growth and at 15 years old he is now just over 5ft. His GHT dose was increased a little and his endocrinologist thinks he has about 18 months of growth left.

I cannot believe we are coming to the end of his growth window but am pleased that we’ve all tried to optimise his height the best that we can. As he gets older he will continue to see his endocrinologist in Southampton once a year.

Due to my time and focus needing to be on James at the moment (as well as work, his sister and needs of aging parents) I’ve sadly now stepped down as a trustee of the CGF, but I will forever remain indebted for the guidance and support we received in the early years and for the wonderful families and children we have met and have become friends.

I will continue to update on James’ story (while he’s happy for me to continue to do so) and am always happy to answer any questions people may have.

I often read posts on socials from families having such similar experiences to us and I will always be available to support and share our experiences and knowledge if it is of help to others as our fantastic children and young adults amaze the world with their resilience, courage and bravery.
Update on Syke
By her mum, Jessicas Watts, CGF trustee and a home educator

Panhypopituitarism

Skye was eventually diagnosed with Panhypopituitarism at 2 years old, at GOSH, after being seen by multiple specialists at our local hospital.

She was the size of a 6-month-old baby, could walk and talk, and had plenty of confidence and sass!

The results of a stimulation test, which we got on the same day as the test, showed that Skye had no GH. Skye was recruited into a study by Dr Webb, and she started GH treatment on her third birthday. At the time of her diagnosis, an MRI scan showed that Skye’s pituitary gland was back-to-front and deformed.

Although initial treatment was just GH therapy, we were advised that it was likely that Skye would lose other hormone functions, as she grew: at 7 years old, she lost her cortisol, at 13 years old, she lost her thyroid function, and she didn’t go through puberty unaided.

Skye is now 17 years old, has stopped growing, and exceeded her mid-parental height target. Also, despite having a full diagnosis of septa optic dysplasia, Skye doesn’t have significant visual impairment.

School was incredibly challenging for Skye, and she was bullied through primary and at the beginning of secondary school. Some of her former primary school classmates continued to bully Skye, with threatening and nasty phone calls, even though they were in different secondary schools.

Unfortunately, some of the abusive calls required the intervention of the police, who were obliged to press charges.
Skye attended a secondary school, out of the catchment area, because of its superb medical facilities. By this time, however, Skye’s condition was extremely unstable, and she was having a crisis almost every month. The emotional pressures of school made Skye’s condition worse, and, halfway through year 8, we took the decision to home educate her.

We were able to access medical tuition through the LA: she received 6 hours per week expert tuition in english, mathematics, and science. We organised the remainder of learning: art, textiles, and sports in the form of horse riding.

Skye thrived and I can honestly say it was the best decision we could have made; one we wish we had taken earlier. Skye’s tuition increased as she got closer to GCSEs, and advocated by an excellent medical tuition team, she did well in her GCSE exams in 2022.

By what would have been year 11, her love for horses had become a huge part of Skye’s life, and she indicated that she would love to pursue a career that involved working with horses. We investigated equine related college courses and made appointments for private tours at two, local colleges.

However, after our visit to the first college, and having explained Skye’s medical needs, we were devastated to be told that the college deemed the course too dangerous for Skye and wouldn’t even consider her for an interview. Skye was so disappointed and, as we anticipated the same response, we decided not to visit the second college.

However, after sharing our college experience with the medical tuition team, they informed me that it was illegal to exclude students on medical needs and provided me with the relevant legislation for children with medical needs and disability in schools.

Department for Education’s ‘Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England’ can be viewed through the QR code, right.

I was genuinely shocked by what I read and found it incredible that, all through primary and secondary school, Skye had been excluded from day trips unless my husband or myself also attended, and excluded from all residential trips; we had been told that risk assessments, including council risk assessments, deemed it too high risk. I have certainly learned a lesson and I will never allow her to be treated like this again. This mama bear woke up!
Understandably, I think, Skye wasn’t keen to go back to the first college, so we made an appointment at the second college, where the whole experience, and our approach, was different. Skye clearly impressed the course tutor with her enthusiasm and knowledge and the college was clearly willing to offer her place, for the coming September. However, their position, once again, changed immediately when I told them about her condition, and explained her medical needs. The course manager acknowledged Skye’s promise but expressed his reluctance of accepting her onto the course, based on the dangers of working with horses, and the risks and consequence of Skye having a crisis in a stable. I counted to ten, before mounting my challenge: I was determined, even if they had excluded other students for similar reasons, it was not going to happen to Skye.

I questioned them on their acceptance of diabetic students or students with epilepsy and argued that Skye’s acceptance should only be made by the college, based on her meeting the course requirements. Finally, I made the legal case and told them it was illegal to reject Skye on medical grounds and that it was their responsibility to make things as safe as possible for Skye; I quoted the guidelines and explained that they couldn’t treat her differently to any student. I am pleased to say that Skye applied for the course and secured her place. It felt as if we had won the lottery and, just before she sat her exams, we bought Skye a pony, Stanley. Skye and Stanley quickly developed an amazing bond.

Skye joined the level 2 course in September 2023, and excelled. She passed the course with distinction, something we never believed we would see. However, Skye did experience issues with some students and decided not to go back to college this year, and instead, chose to continue her ongoing equine training at the yard where Stanley lives. The team at the yard are exceptional and totally understand Skye’s needs, especially her need for time to process instruction and to adapt to changes. Skye has now taken on the responsibility for, and is building a close relationship with, a second horse she is training.

As parents, we worry about where our children will fit into the world. It took me a long time to realise that not every child has to follow the same journey through education. Looking back, I would probably have started home education a lot sooner. I am incredibly grateful to the medical tuition team for all their support and for their sharing of the legal guidelines. I certainly wouldn’t change a thing about Skye and who she is. She is an amazing young person who knows what she wants and is working towards where she wants to be.
Christmas has come and gone and hopefully warmer times are ahead.

Robert and Emily played host at Christmas and we got to spend some quality time with William.

William is progressing well and we continue to look after him on a Friday. He is now 17 months, walking and is chatting away, not that we understand too much yet.

Robert has recently changed jobs and he has moved on to Cushman & Wakefield as an Associate in Commercial Lease Advisory at their Birmingham Office. He seems much happier and should stay for a long time and progress his career there.

William is still being carefully monitored by the local hospital. His measurements are good for both height and weight so it seems less and less likely that he has inherited GHD.

Work continues on their property with the most recent project being a new roof as the old one was leaking. At least now they can crack on with the inside of the house without having to worry about it getting wet.

Robert and Emily both turn 30 this year so no doubt there will some celebrations. Where has the time gone?
Volunteering at the CGF

Opportunities to get involved with our work!

As our work supporting children and families continues to expand, we’ve got some exciting volunteering opportunities within our charity.

We’ve popped details below and if there’s any opportunities you’d like to discuss further please do get in touch with us at volunteer@childgrowthfoundation.org.

Peer Support Group Leader

Our founding peer support group has been launched in Northern Ireland, led by terrific volunteer group leader Sarah Wheelhouse, and we’re in touch with more fantastic new volunteers looking to set up other groups.

This volunteer role is for individuals interested in setting up a peer support group, be it in your local area or to hold virtually, and for a specific condition or to support various conditions.

Trusteeship

We have a dedicated and enthusiastic Board of Trustees, who play a vital role in the governance and strategic vision of our organisation. We will be launching trustee recruitment in the near future for individuals to join this voluntary Board, and in particular we are keen to hear from those with knowledge in and/or experience of Fundraising, HR, Digital or Marketing.

Youth Ambassador

As Lisa shared in the nursing update on page 9, we have an opportunity open to young people aged 16-25 years who have, or had, experience of a growth condition or concern, to become a Youth Ambassador and help with our new Youth Ambassador Programme to make sure that young people’s voices are heard on matters that affect you.

Meet Up Host

Our first Meet Up event took place in Gulliver’s Land Milton Keynes in February - a wonderful day with over 50 people joining to meet other children and families. We’re looking to host these Meet Ups across the UK at a range of locations and venues, and we would love to hear from people who would be interested in working with us to organise a Meet Up event in your area.
If you’d like to share your story, news, updates or insights in our newsletter or other communications we’d love to hear from you!

Please get in touch with us at news@childgrowthfoundation.org.

If you have any feedback on this newsletter, or previous newsletters, we’d really welcome your feedback at news@childgrowthfoundation.org.

Likewise, if you have any ideas or suggestions for what you’d like to see featured in future editions of the newsletter please do get in touch to share these with us!
Join our weekly lottery from £1 a week and be in with a chance to win a £25,000 jackpot while supporting our work to improve the lives of children, adults and families affected by child growth conditions. Scan the QR code, right, to join or to find out more.