Winter
2025

CGF News

Making a difference wherever growth is a concern

This edition is produced with thanks
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Child
Growth
Foundation

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Thanks so much to all those who've contributed to the Winter 2025 edition of CGF News, it's really appreciated! If you'd like to share your story, feature an update for the child growth community in a future edition, or if there's anything else you'd like to discuss about CGF News please get in touch with our friendly team at: news@childgrowthfoundation.org

Have your say!

We'd really value your input and thoughts on our CGF News to make sure we bring you, our readers, the content you want to see and read!

Please take our short, anonymous survey to share your views with us on CGF News at: https://forms.office.com/e/Q36WbH3ZkU or by scanning the QR code, right. Your responses will help shape our future editions.

Disclaimer:

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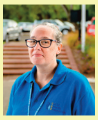
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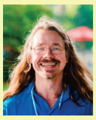
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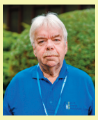
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Updates from the CGF team

From our Chair


Jeff Bolton, Chair of Trustees

I hope you have all had a lovely summer and autumn.

At the start of the summer, in June, the CGF staff and trustees held an annual planning meeting, and I am pleased to have this opportunity to share highlights of our planned programmes and activities, for the next twelve months.

I want to immediately reassure everyone that the CGF annual convention will remain a major event in the CGF calendar. Unfortunately, and due to the unforeseen temporary closure of our convention's usual Warwick venue, we were obliged to postpone this year's convention to sometime in 2026. While seeking a new venue, we explored different dates and additional facilities to improve the meeting programme. We will, of course, still retain the principal sessions that families value and give them the opportunity to meet and ask questions of the medical experts and to meet, make friends and discuss their challenges with other families.

The CGF understands the importance of, and values, family interaction and will expand events that encourage informal discussions among families. The CGF 'Virtual Cuppa & Chats', hosted by Sally and Lisa, our specialist nurses, have been widely appreciated and Sally and Lisa will increase the number of these type of meetings, to include some sessions when an expert will be invited to present and discuss a specific topic of interest.

The CGF will also expand its programme of family 'Meet Ups' at a range of popular UK family venues. Four Meet Ups have taken place this year, at Gulliver's World Warrington, LEGOLAND Windsor, LEGOLAND Discovery Centre Birmingham and SEA LIFE Manchester. The CGF was pleased, courtesy of Merlin's Magic Wand Children's Charity, to be able to provide free tickets to the latter three Meet Ups, and it was very pleasing and enjoyable for our team to meet up with so many CGF members and the child growth community.

The CGF encourages families to join as full members and welcomes new participants to the charity. There are a range of benefits to becoming a member, and, most importantly, expanding our membership will help the CGF to fund its ongoing and expanding support to even more affected families. A CGF awareness campaign, planned for the future, aims to promote early detection of growth conditions and boost membership and volunteer numbers.

I have highlighted the CGF's commitment to play a key role driving the earlier detection, referral, and diagnosis of growth conditions, in previous newsletters, and this will remain a key focus. We are planning, therefore, to raise the visibility and profile of the CGF's growth condition awareness campaign and expand our GP education programme. The CGF is helping GPs better understand growth conditions and respond more effectively to family concerns about child growth.

We are planning, therefore, to increase our presence at GP meetings and to ensure that as many general practitioners as possible can access the high-quality webinars developed last year by Professor Helen Storr and Professor Justin Davies.

The CGF understands and recognises that paediatricians may also sometimes contribute to a delayed diagnosis and referral of a child to the growth expert and the CGF aims, with the expert support of our medical experts, to develop a programme of appropriate education and information to reduce the incidence of this happening.

The CGF also believes schools could be important for, and play a pivotal role in, the early detection of potential growth conditions. Being mindful of the sensitivities of both teaching staff and parents, we will investigate the possibility for developing a schools' growth education and awareness programme that will be heavily focused on the role and responsibility of the school nurse. We hope to launch this programme next year, following our discussions.

We anticipate, and sincerely, hope the CGF's targeting of information at the different professional groups will result in an increase in the number of families reaching out to the CGF, and the CGF will respond with an expansion of its support through its Support Line, an expansion of its information booklets and literature, and a rebuild of the CGF website. Our aim is to improve the usability of our website, with increased support for families during the pre-diagnosis period of growth conditions and the inclusion of topics that are of increasing interest and relevance to families.

Finally, I want to say a big thank you and express the CGF's sincere appreciation to everyone who supports us in our fundraising efforts. Charities are currently facing significant financial challenges, and we have developed a year's programme of fundraising events, to hopefully appeal to a range of interests and abilities of anyone who is able to support us. I and my CGF colleagues hope we will have the opportunity to meet you at one of these or another CGF event.

We need and rely on your support and if you aren't a member already, we invite you to become a full CGF member.

Many thanks and best wishes to all, Jeff

Notice of our AGM

Join us at our virtual Annual General Meeting (AGM) on Tuesday 3rd February 2026, at 7pm (GMT). At our AGM we'll share important reflections and updates from the CGF as we report on the past year and look ahead to our upcoming plans for our charity.

Full, paid members of the CGF have voting powers at this meeting, with community members and non-members very welcome to attend as observers. 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. To register to attend for free please contact: events@childgrowthfoundation.org

Update from Catriona

Catriona Taylor, Charity Manager

As 2025 draws to a close it's a great time to reflect back on the fantastic support and activities the CGF has delivered to make a difference wherever growth is a concern.

Including the expansion of our brilliant family friendly Meet Up events, which our team have loved hosting to bring together children and their families, our wonderful Virtual Cuppa & Chats, and our amazingly active closed Facebook groups - all examples of how our team are faciliating safe, welcoming spaces for peer support for children and parent carers.

Children's Growth Awareness Week and International Children's Growth Awareness Day took place in September and as always provided an important opportunity to raise vital awareness of growth conditions and growth concerns. We shared a board full of resources, available here: `trello.com/b/LI62Wozm/cgaw-icgad-2025` and we had some wonderful 'A day in the life of' stories shared with us from those affected by growth conditions, which you can catch up on here: `childgrowthfoundation.org/day-in-the-life`

The team have been working tirelessly to continuiously create and update a number of resources throughout the year, including videos, infographics, booklets, factsheets and guides, alongside pages on our website. Lisa and Sally share more about some of our latest resources, and we have our latest infographics featured here in pages 16 and 17. We have a new webpage on other other conditions which can/may affect growth at: `childgrowthfoundation.org/other-conditions` which we'll continue to add to. And whilst we're a UK charity we have a consistently high number of visitors to our site each month from outside of the UK and so we have created a dedicated page for those visiting our site from overseas, at: `childgrowthfoundation.org/overseas`

Importantly we've also been working on raising vital funds to sustain and support our work into 2026 and beyond, and we've got some great opportunities to get involved, including some festive fundraising opportunities and fun challenges coming up next year.

Collaboration remains an integral part of our approach and it was lovely to see so many Society for Endocrinology (SfE) Patient Support Groups, right, at SfE's British Endocrine Society event in Harrogate earlier this year.

This is my last newsletter as I finish my time at the CGF at the end of December, and I leave things in the extremely capable hands of our terrific team. I'm in awe every day at their hard work, determination and unwaivering commitment, puttting the child growth community at the heart of everything they do. Our staff, trustees, volunteers, Medical Advisors, Youth Ambassadors, members, fundraisers, donors, supporters and so many others make the CGF a truly special charity and it's been such a pleasure to be part of Team CGF over the past three years. Thank you! Wishing you all a wonderful Christmas and all the very best for 2026.

Update from our nursing team

Sally Majid, Growth Nurse Specialist

Lisa Hill, Paediatric Endocrine Nurse Specialist

SUPPORT

Virtual Cuppa & Chats

Since our last newsletter we have hosted six Virtual Cuppa & Chat events. These continue to be popular and are well attended by families with and without a diagnosis, wishing to meet and talk through their current challenges. Certain topics come up in conversation fairly frequently, so we decided to trial a themed event in June to talk about injections and a Silver-Russell syndrome themed event in October, which were both was very successful. We have plans to do more themed events and we'd love to hear what sort of topics would be of interest to you. Please get in touch by email at: `support@childgrowthfoundation.org` and let us know your ideas for specific themes, all ideas are welcome.

Peer Support Groups

A huge thank you to our amazing group of volunteers running our Peer Support Groups, it's incredible to see so many people keen to join them. The value we witness at connecting families with shared experiences to build friendships and have fun is fantastic. Please visit our website to find out more on how to join at: `childgrowthfoundation.org/peer-support`

We would love to have more groups at different locations across the country, so if you are interested in being a group leader, please email us at: `volunteer@childgrowthfoundation.org`

Support Line

Our Support Line continues to be available by both email and phone. Over the last 6 months we have had 291 contacts with families seeking support, advice and guidance. Some of these are families who have contacted us multiple times, something that we encourage to ensure that no queries or concerns are left unanswered.

We would love to get more feedback from those who have used the Support Line to review if there's anything we need to change or improve. If you have made contact via the Support Line you can find the form by scanning the blue QR code below:

We now have a small number of bookable Support Line slots available each month. Slots are available for the month ahead (e.g. slots for January 2026 available in December 2025) through the yellow QR code below, or at: `childgrowthfoundation.org/bookings`

Sally with the Harlow Solutions team at the RCPCH conference

Sally with Laura from our team at Society for Endocrinology's Endocrine Academy's event

COLLABORATING WITH HEALTHCARE PROFESSIONALS

RCPCH Conference

In March we were very lucky to be invited by Harlow Solutions to share their stand at the Royal College of Paediatrics and Child Health (RCPCH) conference. RCPCH are the membership body for paediatricians in the UK and around the world. The theme for this year's conference was 'Future child health: innovate, integrate and inspire' and featured a dedicated area on childhood rare diseases. The event was a brilliant opportunity to share our materials and talk to paediatricians from across the UK.

We connected with other patient support groups in attendance, many of whom we have never met or worked with before. We particularly valued sharing ideas of how we support our rare community and identifying ways we can collaborate to deliver greater impact, reaching as many families as possible and provide the most appropriate, meaningful support.

Healthcare professionals resources

We have a refreshed and updated our Healthcare Professionals area on our website at: `childgrowthfoundation.org/hcp` with resources and links which we will continue to add to. Our new Healthcare Professionals (HCP) ordering page at: `childgrowthfoundation.org/hcp-order-form` enables organisations to order our resources to share with their patients with ease. Also available to order are our new 'How to measure' infographics, developed to ensure accurate, consistent growth measurements, which is so vital for assessment, diagnosis and treatment for our whole community.

ENDOCRINE NURSES UPDATE

To spread the word about the new Healthcare Professionals area on the website, we took the opportunity to update paediatric endocrine nurses nationally about the latest resources that are available and the support that can be offered to the families that they see in clinic.

UPDATED RESOURCES

We both continue to work on updating current resources and developing new ones including the Growth Monitoring Guide, shown on the following page (page 10). Currently we are near completion of our new Sotos syndrome information booklet, plus new puberty resources.

We're delighted to share that our new resource 'Childhood growth: A parent carer guide' is here.

This guide is packed with information including typical growth in childhood and puberty, monitoring growth and measuring at home, head circumference measurements, concerns if you're child is smaller or taller than expected, who to approach if you have concerns...and much more!

Available to read and download at:
`childgrowthfoundation.org/growth-guide`

Mental health and emotional wellbeing webpage

We feel incredibly privileged to have a fantastic Clinical Psychologist on our Medical Advisory Committee, who kindly reviewed some updates and changes we made to the revamped mental health and emotional wellbeing page on our website. We hope you all have a chance to read and explore the information and some of the resources we have shared here, available at: `childgrowthfoundation.org/mental-health`

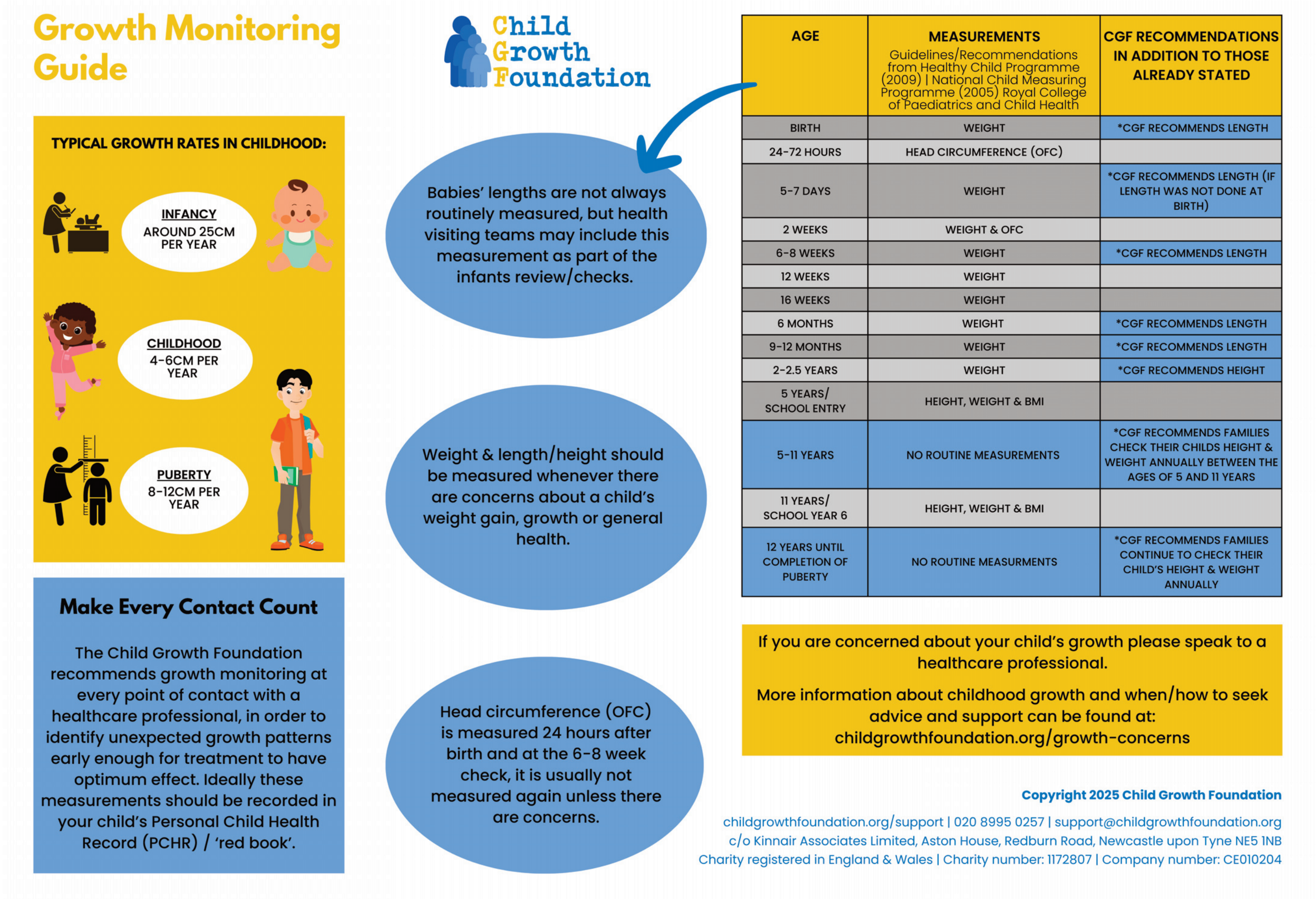
VIDEOS

Our library of videos and short videos that we share on social media can also be found on our website at: `childgrowthfoundation.org/videos` and on our YouTube channel at: `youtube.com/@childgrowthfoundation`

Shout out for videos for injection resource

We would love to put together a video on giving injections and would really appreciate anyone who has (or would record) a short clip of their child having an injection. We feel it would be a huge benefit to those who are just starting injections to see others who are already doing it. No faces or names need to be included.

If you have something you would be happy for us to use please let us know by emailing us at: `support@childgrowthfoundation.org`



Growth Monitoring Guide

Child Growth Foundation

TYPICAL GROWTH RATES IN CHILDHOOD:

INFANCY
AROUND 25CM PER YEAR

CHILDHOOD
4-6CM PER YEAR

PUBERTY
8-12CM PER YEAR

Make Every Contact Count

The Child Growth Foundation recommends growth monitoring at every point of contact with a healthcare professional, in order to identify unexpected growth patterns early enough for treatment to have optimum effect. Ideally these measurements should be recorded in your child's Personal Child Health Record (PCHR) / 'red book'.

Babies' lengths are not always routinely measured, but health visiting teams may include this measurement as part of the infants review/checks.

Weight & length/height should be measured whenever there are concerns about a child's weight gain, growth or general health.

Head circumference (OFC) is measured 24 hours after birth and at the 6-8 week check, it is usually not measured again unless there are concerns.

AGE	MEASUREMENTS Guidelines/Recommendations from Healthy Child Programme (2009) | National Child Measuring Programme (2005) Royal College of Paediatrics and Child Health	CGF RECOMMENDATIONS IN ADDITION TO THOSE ALREADY STATED
BIRTH	WEIGHT	*CGF RECOMMENDS LENGTH
24-72 HOURS	HEAD CIRCUMFERENCE (OFC)	
5-7 DAYS	WEIGHT	*CGF RECOMMENDS LENGTH (IF LENGTH WAS NOT DONE AT BIRTH)
2 WEEKS	WEIGHT & OFC	
6-8 WEEKS	WEIGHT	*CGF RECOMMENDS LENGTH
12 WEEKS	WEIGHT	
16 WEEKS	WEIGHT	
6 MONTHS	WEIGHT	*CGF RECOMMENDS LENGTH
9-12 MONTHS	WEIGHT	*CGF RECOMMENDS LENGTH
2-2.5 YEARS	WEIGHT	*CGF RECOMMENDS HEIGHT
5 YEARS/ SCHOOL ENTRY	HEIGHT, WEIGHT & BMI	
5-11 YEARS	NO ROUTINE MEASUREMENTS	*CGF RECOMMENDS FAMILIES CHECK THEIR CHILDS HEIGHT & WEIGHT ANNUALLY BETWEEN THE AGES OF 5 AND 11 YEARS
11 YEARS/ SCHOOL YEAR 6	HEIGHT, WEIGHT & BMI	
12 YEARS UNTIL COMPLETION OF PUBERTY	NO ROUTINE MEASURMENTS	*CGF RECOMMENDS FAMILIES CONTINUE TO CHECK THEIR CHILD'S HEIGHT & WEIGHT ANNUALLY

If you are concerned about your child's growth please speak to a healthcare professional.

More information about childhood growth and when/how to seek advice and support can be found at: childgrowthfoundation.org/growth-concerns

childgrowthfoundation.org/support | 020 8995 0257 | support@childgrowthfoundation.org
c/o Kinnair Associates Limited, Aston House, Redburn Road, Newcastle upon Tyne NE5 1NB
Charity registered in England & Wales | Charity number: 1172807 | Company number: CE010204

Our Support Line

Our nurse led Support Line is available to anyone affected by a growth condition and those concerned about their child's growth. We are here to listen and support you. The Support Line is also available to healthcare professionals looking for information.

Complete our Support Line online contact form at:
childgrowthfoundation.org/supportline
Email us at: support@childgrowthfoundation.org
Call our dedicated Support Line number on: 020 8995 0257
Book a slot at: childgrowthfoundation.org/bookings
Scan the QR code, right.

Support Line Privacy Statement

By contacting the CGF 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: childgrowthfoundation.org/supportlineprivacy

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PROF MEHUL DATTANI

PROF JUSTIN DAVIES

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DR FENELLA JOHNSTONE

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EMMA SNOW

DR NADIA SOMERS

PROF HELEN L STORR

PROF KATE TATTON-BROWN

PROF KAREN TEMPLE

DR EMMA WAKELING

RUTH WYLLIE

CGF's Medical Advisors

Thanks so much to our above experts, who together form the CGF's Medical Advisory Committee.

They provide expert guidance to the CGF team and get involved in a range of projects with our charity to support children, young people, adults, families and fellow healthcare professionals.

Magical Meet Ups

Our Meet Ups are hosted by the CGF team and bring the growth community together for a fun, family friendly day out.

Laura and Jessica from our team plan our Meet Up events across different locations and dates, to bring familiar and new faces together for these special days out.

In 2025 we've hosted four Meet Ups, taking place at Gulliver's World Warrington in February, LEGOLAND Windsor in May, LEGOLAND Discovery Centre Birmingham in August and SEA LIFE Manchester in November. These wonderful events have brought together more than 180 children and families this year - thanks so much to everyone involved for making these such terrific events!

Merlin's Magic Wand

Thank you so much to Merlin's Magic Wand Children's Charity for their support through their Magical Days Out opportunity, providing free tickets for our Meet Ups at LEGOLAND Windsor, LEGOLAND Discovery Centre Birmingham and SEA LIFE Manchester. It's hugely appreciated, and is wonderful for our charity to be able to share this magic with the child growth community.

2026 Meet Ups

We'll announce upcoming Meet Ups on the dedicated Meet Ups page on our website, available by scanning the QR code, right, or by visiting: `childgrowthfoundation.org/meet-ups`

> **"I have attended a lot of conferences, meet ups, scientific events with a vast majority of different charities and this was by far the best. The staff at CGF are extremely welcoming, easy to get on with, caring, understanding and kind. It was an entire breath of fresh air to meet children in such similar circumstances. I have attended conferences for my son's specific disease and never felt more isolated because all the children could walk and talk and my son appeared so differently. Without the CGF we would have no support, no network and no understanding."**
>
> -Meet Up attendee feedback

Magical moments

Medical community updates

The Generation Study

A while back we shared some information about The Generation Study and our involvement.

As the study is now up and running, we thought it would be an opportune time to share some more details and progress updates.

The Generation Study is a groundbreaking research study which will sequence the genomes of 100,000 newborn babies. It is run by Genomics England in partnership with NHS England to understand whether diagnosis and treatment can be improved for rare genetic conditions.

The study has been developed following extensive consultation with the public, parents and families affected by rare conditions as well as healthcare professionals, policy makers and scientists. It involves babies born in several different hospitals across England. A current list of participating hospitals can be found here: generationstudy.co.uk/register-your-interest/participating-hospitals

The CGF has been involved by attending consultations, training and information events and reviewing patient information for the conditions included in the study which affect our community. We have also been preparing ourselves for potential calls to our support line for anyone who receives a diagnosis and/or condition suspected result after taking part in this study.

There are thousands of potential conditions that can be tested for through genome sequencing. Careful consideration was given by Genomics England when deciding which conditions should be looked for in the Generation Study. Four principles were designed to guide the team's selecting which conditions will be looked for. More information on these principles can be found here: genomicsengland.co.uk/initiatives/newborns/choosing-conditions

Currently there are over 200 conditions being tested for in this study, the ones included which affect the CGF community are certain types of Growth Hormone Deficiency, IGF1 deficiency and Hypopituitarism. You will find a complete list of all the conditions included here: genomicsengland.co.uk/initiatives/newborns/choosing-conditions/conditions-list-generation-study

For anyone interested in taking part in this study, more information can be found here: generationstudy.co.uk/overview-of-the-study

RARE Patient Passport

We are delighted to have joined the growing global network of patient groups partnering with CamRARE (Cambridge Rare Disease Network) to bring their 'This Is Me' Rare Patient Passport to the child growth community, which includes tools to communicate your rare condition, or your child's rare condition, to new people.

Sign up for yours/your child's here: `camrarediseas.org/patient-passport`

RARE
patient
passport

THIS IS
me

camRARE

....have worked with families & clinicians to create a fillable, personalised **health & care passport** to help communicate your key medical & care information in an emergency, away from home or when meeting new people.

GET
YOUR
PASSPORT

Child
Growth
Foundation

IN PARTNERSHIP WITH

Since launching there have been over 2,000 applications and CamRARE have partnered with more than 60 patient groups worldwide – we are so pleased to be supporting this global initiative as part of our work to make a difference wherever growth is a concern.

Do you have a study, survey or research project to share?

If you are the organiser of a study, survey or research project you would like to share with our community, please contact our team at: `research@childgrowthfoundation.org` and we can share our request form with you to complete.

Our latest infographics...

Child Growth Foundation

Tips for using AI and search tools to find information about growth conditions

Artificial Intelligence (AI), including tools like ChatGPT or AI-enhanced Google searches, can be useful for finding quick answers online. But when it comes to your child's health and growth, it's important to know how to use these tools safely and wisely. Here are some tips from the Child Growth Foundation (CGF) to help you get accurate, reliable information and to help avoid risks.

Start with trusted sources first

Before turning to AI tools, check websites run by:
- The NHS at nhs.uk
- Reputable charities like the CGF
- Registered health organisations or research institutions

AI tools are not a substitute for professional advice. Use them to understand general information, not to make health decisions.

Use specific, clear questions

The more precise your question, the more helpful the answer:
- Instead of asking 'Why is my child short?'
- Try: 'What are possible causes of short stature in children, and when should I seek medical advice?'

Avoid overly broad or vague questions, which may result in misleading answers.

Check dates and references

AI can sometimes give outdated advice or refer to studies or guidelines that no longer apply.
Always check:
- The publication date: is it recent?
- The source: is it credible?
- Whether the advice is UK specific, especially important for medical care.

Combine AI tools with professional support

AI can help you:
- Explore questions to ask your doctor or other healthcare professionals
- Learn about how growth conditions are managed

But your child's healthcare team is the best source for advice, diagnosis, and next steps.

Be aware of global differences

We are a UK based charity. Some AI tools give information based on guidelines from the US or other countries. These might not reflect how the NHS works. Always check whether the advice matches UK healthcare practices.

Be aware: AI can 'sound confident' but be wrong

AI tools like ChatGPT may give answers that seem reliable but:
- They don't always use up to date or verified sources.
- They can make mistakes or 'hallucinate' (generate incorrect information).
- They can miss important context specific to your child's needs.

Always double-check any AI generated advice against professional medical sources or with your healthcare provider.

Ask AI to list sources or trusted organisations

You can say, for example: 'Can you give me information from the NHS or a UK based charity about Growth Hormone Deficiency?'
This encourages the AI to guide you to recognised, trustworthy websites.

Be cautious with personal or diagnostic advice

AI is not a doctor. It cannot:
- Diagnose a condition
- Interpret test or scan results
- Recommend treatment specific to your child

If you're worried about your child's growth speak with your GP or contact the CGF.

Talk to your child about what they read online

If your child or teen is searching for answers online, help them understand:
- Not everything they read online is true
- They can come to you or a healthcare professional with their worries
- It's OK to be curious, but it's important to get accurate support and information

You're not alone - support is here

Our charity is here to help you with:
- Detailed resources
- Peer support
- Guidance from healthcare professionals

Please contact us or visit: childgrowthfoundation.org

support@childgrowthfoundation.org | 020 8995 0257 | childgrowthfoundation.org
Child Growth Foundation, c/o Kinnair Associates Limited, Aston House, Redburn Road, Newcastle upon Tyne NE5 1NB
Charity registered in England & Wales | Charity number: 1172807 | Company number: CE010204

Top tips: Travelling with medication

From parents, for parents

Child Growth Foundation

- Ask your consultant and/or pharmacist to provide a letter for travelling with medication.
- Check with a pharmacist whether the medication can be X-rayed. If not, ensure this is included in the letter.
- Check you medication’s storage instructions. E.g. Can it be left out of the fridge? Or does it have to be stored below a certain temperature at all times?
- Ask your endocrine nurse if there are other devices / syringe available that are easier to travel with.
- Ask the pharmacy that supplies your medication if they can supply you with a cool bag to help with travelling with medication.
- Some medicines that are legal in the UK may be restricted abroad. Check the rules of your destination (and any countries you’re transiting through) before you travel.

For further support please get in touch with our nurse led Support Line:

w: www.childgrowthfoundation.org/support
t: 020 8995 0257
e: support@childgrowthfoundation.org

Child Growth Foundation, c/o Kinnair Associates Limited, Aston House, Redburn Road, Newcastle upon Tyne NE5 1NB
Charity registered in England & Wales | Charity number: 1172807 | Company number: CE010204

Membership

Becoming a member

When you become a full, paid member of the CGF you are not only make a real and lasting contribution to our charity's work but there are also various benefits to you, including:

- A printed copy of this bi-annual newsletter, CGF News, delivered to your door
- Member-only benefits for convention including early bird booking
- Access to the members-only area of our website
- Voting powers at our Annual General Meeting
- Early access to a number of new CGF resources before their release

Full membership costs

- £25 a year to UK residents
- £30 for those living overseas

Find out more at: childgrowthfoundation.org/membership
or scan the QR code, right.

Community membership

If you have family, friends or colleagues who aren't looking to be a full member at this present time but would like to be a part of our CGF community, they can join our charity as a free community member at: childgrowthfoundation.org/register

As part of our community membership they'll receive our email communications and updates including a digital copy of this bi-annual CGF Newsletter emailed to their inbox.

Renewing membership

Thank you so much to our members for your wonderful support. This support you provide through new or continued membership helps us deliver our range of services to families affected by rare growth conditions and those seeking a diagnosis, to support healthcare professionals, and to raise vital awareness.

There are a number of ways you can pay your membership:

By Standing Order

Account Name: Child Growth Foundation
Sort Code: 23 05 80
Account Number: 24218095

By card

Via our website: childgrowthfoundation.org/membership

or scan the blue QR code, right.

By cheque

Please make cheques payable to **Child Growth Foundation** and post to us at:

Child Growth Foundation
c/o Kinnair Associates Limited
Aston House, Redburn Road
Newcastle upon Tyne NE5 1NB

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 yellow QR code, right.

For any queries regarding membership please contact: laura.roy@childgrowthfoundation.org

Kids corner

CGF's colour wordsearch

C	S	O	S	T	Z	Z	U	T	T	I	V	Z	W	G	H	H	B	G	M
Y	E	G	Z	P	Y	T	S	Y	O	T	Y	F	K	O	R	K	R	L	U
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Q	C	N	Q	O	G	I	D	N	I	F	A	B	G	W	T	H	L	C	I

Find these colours in the above grid...

ORANGE	BLACK	PURPLE	NAVY
TURQUOISE	BROWN	GREEN	PINK
SILVER	CYAN	YELLOW	VIOLET
INDIGO	GREY	WHITE	GOLD
BRONZE	BEIGE	BLUE	RED

Answers on page 31

CGF's hobbies crossword

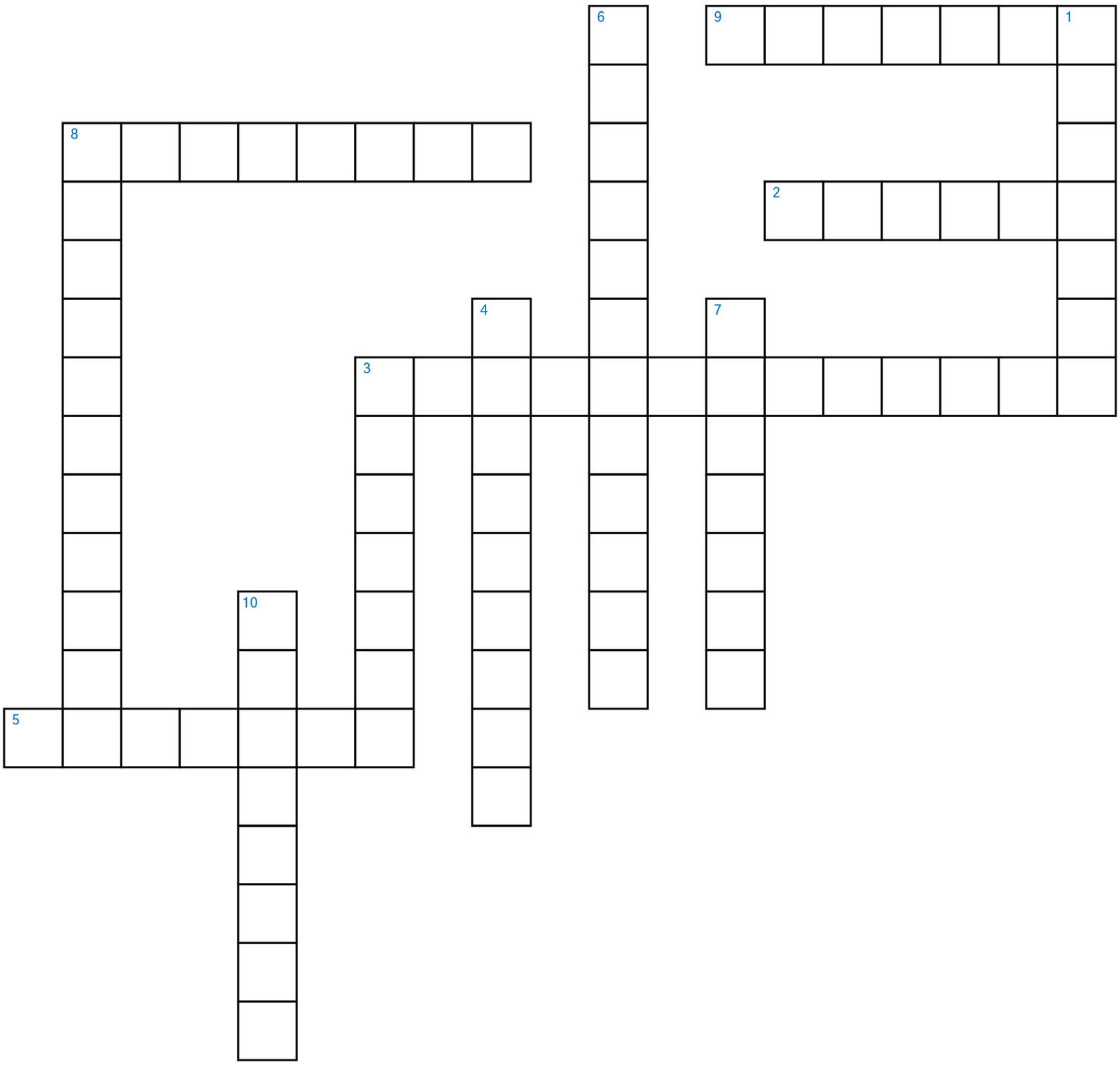
Find these hobbies in the below crossword...

Down:

1. Producing musical vocal sounds.
3. Riding ocean waves board.
4. Cultivating plants and flowers.
6. Helping others for free.
7. Preparing food dishes.
8. Capturing images with camera.
10. Propelling body through water.

Across:

2. Stitching fabric with needle.
3. Riding on wheeled board.
5. Riding bicycles for sport.
8. Applying colour to surface.
9. Solving complex brain teasers.



Answers on page 31

Fantastic fundraising!

River

River Luders has previously done some awesome fundraising for our charity and we're delighted to share his latest brilliant fundraising raised £400! Huge thanks to River took on his school half marathon challenge, in May and kindly supported the CGF through his JustGiving page at: justgiving.com/page/frankie-luders-4

Marine

Thanks so much to Marine Joly who took on the Great South Run this October, raising funds for the CGF at: ajbellgreatsouthrun2025.enthuse.com/pf/marine-joly-for-rose. Marine took on the 10 mile run, and raised over £760 - amazing!

Tilly

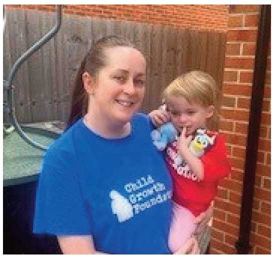
Thanks very much to Tilly Charman who's been undertaking incredible fundraising and running in support of the CGF throughout 2025, with £725 raised! Tilly has taken on the Monikie 10k and Dundee Half Marathon with friend Joanna, and the Dundee Kiltwalk with friend Evelyn, raising funds at: justgiving.com/team/tiilyandjoannarunningforgrowth

The BIG Toddle

We're so grateful to our terrific supporters who took on The BIG Toddle over the second May Bank Holiday weekend and together raised a wonderful £995!

justgiving.com/campaign/the-big-toddle-2025

- Evelyn, who has Russell-Silver syndrome, raised £215 💛
- Eliza, who has Hypopituitarism and Hypothyroidism, raised £355 💛
- CGF Nurse Sally, her dog Winnie, and mum June raised over £380 💛



Royal Parks Half

Five incredible Team CGF runners took on the Royal Parks Half Marathon

On Sunday 12th October 2025, more than 16,000 runners laced up their trainers and took to the streets of London for the Royal Parks Half Marathon. Among them were five amazing runners (shown in the below photos) proudly representing the CGF!

The route took runners through some of London’s most iconic landmarks and beautiful green spaces, and our team showed incredible determination and spirit every step of the way. Together they’ve raised over £3,000 to help us continue supporting children, young people, adults and their families affected by growth conditions and concerns.

Adding to the atmosphere on the day were Sally, Laura and Vanessa, our brilliant CGF cheer squad, who brought the energy, encouragement, and plenty of smiles! Their cheers helped keep our runners motivated and reminded everyone what the CGF community is all about - support, positivity, and heart.

We are so grateful to our runners, our cheer squad, and everyone who sponsored, donated, or came along to cheer. From all of us at the CGF, thank you for running, cheering, and championing our cause, you’ve all made a huge difference to our charity’s work, and we couldn’t be prouder!

Supporting our work

We have so many ways to support our work making a diffference wherever growth is a concern. From a few clicks in a few minutes to set up fundraising, to longer term opportunities to make a lasting impact.

Weekly lottery

Join our weekly lottery from £1 a week at: childgrowthfoundation.org/weekly-lottery and be in with a chance to win £25,000!

Ink cartridge recycling

Recycle your old printer cartridges and our charity receives a donation. Visit: recycle4charity.co.uk and select the CGF as your charity of choice.

Birthday celebrations

Set up a Facebook birthday fundraiser or celebratory JustGiving page at: justgiving.com/childgrowth in aid of the CGF and share with your family and friends asking for donations in lieu of gifts.

Free Will writing service

As a supporter of the CGF, you're eligible for a free, legally-binding Will with FreeWills.co.uk which is checked, vetted and approved by a solicitor. There's no obligation to leave a gift to the CGF, but you may choose to, to enable us to continue our important work. Find out more at: childgrowthfoundation.org/free-wills

Leaving a legacy

Leave a lasting legacy by including a gift in your will to our charity, ensuring your supporting continues to make a difference for children and families for generations to come. To discuss this further please get in touch with us at: fundraising@childgrowthfoundation.org

Your fundraising, donations, membership and more are vital to help continue our support and services to the child growth community.

Fundraising yourself, as a family, with friends, colleagues, or in your local community has a huge impact on the children, young people, adults and families that we are here to support.

If you have any fundraising plans or ideas we'd love to discuss these with you at: fundraising@childgrowthfoundation.org or on 020 8798 2139.

> **"I just wanted to say a big thank you. The information was so helpful. It was a comfort to talk to you and the other parents, I feel less alone with what we are going through."**
>
> -Virtual Cuppa & Chat feedback

Raise funds for us for FREE

with easyfundraising

Join as our supporter today at:

www.easyfundraising.org.uk/support-a-good-cause

Just search for:

Child Growth Foundation

8,000+ retailers will donate to us whenever you shop with them

Argos TESCO JOHN LEWIS ebay JUST EAT

1. Start at the easyfundraising website or app
2. Click out to where you'd like to shop
3. Checkout: prices are exactly the same!
4. The retailer sends a % of your spend to easyfundraising
5. They pass it on to us :)

Plus, you'll get...

- Exclusive retailer offers
- Competitions
- A warm feeling inside!

Over **£60m** raised for UK good causes

£0 extra cost to anyone

Festive fundraising

Give the gift of support this Christmas

This Christmas, help us wrap families in the support they need by donating to our Christmas campaign at: childgrowthfoundation.org/gift

Wrap our families in understanding

£9 could fund a 30 minute Support Line call with one of our nursing team for families with a new diagnosis or a concern.

Wrap our families in connection

£17.50 could fund our nurses running costs to enable one parent/carer to attend a virtual support group Cuppa and Chat.

Wrap our families in guidance

£50 could provide 25 families with condition information guides our nurses send to parents following their child's diagnosis.

Christmas Raffle

Take part in our Christmas Raffle and as well as raising funds towards our range of work for the child growth community, you'll also be in with a chance to win some fab prizes, including an Ocado voucher, a Greggs voucher, and a range of CGF goodies, including our new hoody, a Magnificent Max t-shirt, and a set of our 3 children's storybooks.

Get your tickets at: childgrowthfoundation.org/raffle

Our guide to festive fundraising

Inside our free digital Christmas Fundraising Pack, you'll find everything you need to make your festive fundraising a success – from handy tips and creative ideas to guidance on how to pay in your donations safely and responsibly.

Whether you're baking mince pies, dashing through a fun run, or hosting a Christmas quiz, we're here to cheer you on every step of the way! Read or download your free pack at: childgrowthfoundation.org/christmas-pack

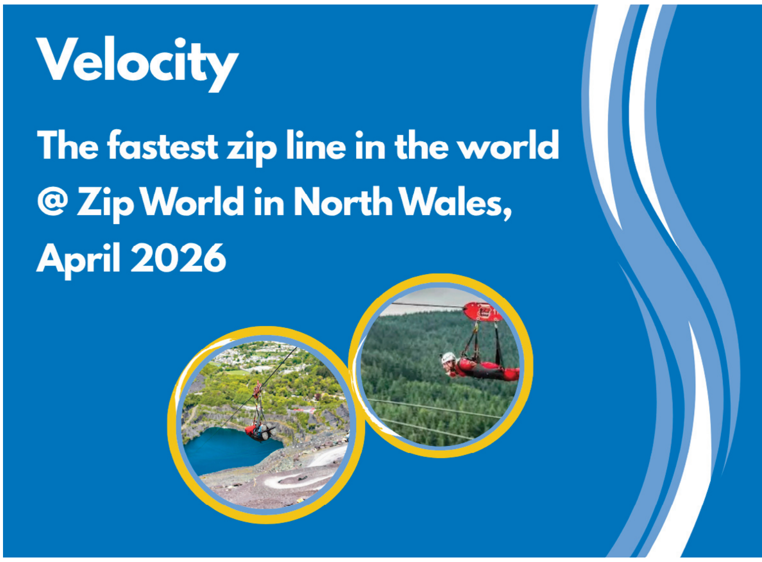
Fundraising in 2026

We've got some great fundraising opportunities coming up in 2026 and we'd love you to get involved!

Are you ready to take on the fastest zip line in the world?

We're calling all thrill-seekers, daredevils, and everyday heroes to join Team CGF and take on Velocity at Zip World – the ultimate adrenaline challenge – all in support of children, young people, adults and their families affected by growth conditions and concerns.

In April 2026 you'll soar over Penrhyn Quarry in North Wales at speeds of up to 100mph, taking in breath-taking views (if you can keep your eyes open 👀) all while raising vital funds for the CGF.



Velocity

The fastest zip line in the world @ Zip World in North Wales, April 2026

Please complete our short expression of interest form below to join the adventure at: `childgrowthfoundation.org/velocity`

Royal Parks Half 2026

After the amazing success of our Royal Parks Half runners this October, we are so excited to again have five free charity places in the 2026 Royal Parks Half Marathon.

The Royal Parks Half, being held on Sunday 11th October 2026, is London's original half marathon. The run follows a beautiful 13.1-mile route and takes in many of the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks – Hyde Park, The Green Park, St James's Park and Kensington Gardens.

We have five free charity places, available on a first come first served basis to fundraisers pledging to raise a minimum of £250 through their CGF charity place. All runners will receive a free CGF running t-shirt or vest, and support from our charity in your fundraising efforts. To sign up for this iconic run: `childgrowthfoundation.org/royal-parks-half`

Inflatable 5K Obstacle Run

Last but not least, we will have places available in the world's largest and best inflatable 5K obstacle run - more details are to follow on our email updates, our website and on our social media channels.

Storybooks from the CGF

Your Height, My Height

Everyone is a different height, we all have different super powers.

With beautifully warm and colourful illustrations this uplifting, positive book for children and families Your Height, My Height celebrates the uniqueness of our heights, as children play, learn and grow together.

childgrowthfoundation.org/yhmh

Magnificent Max

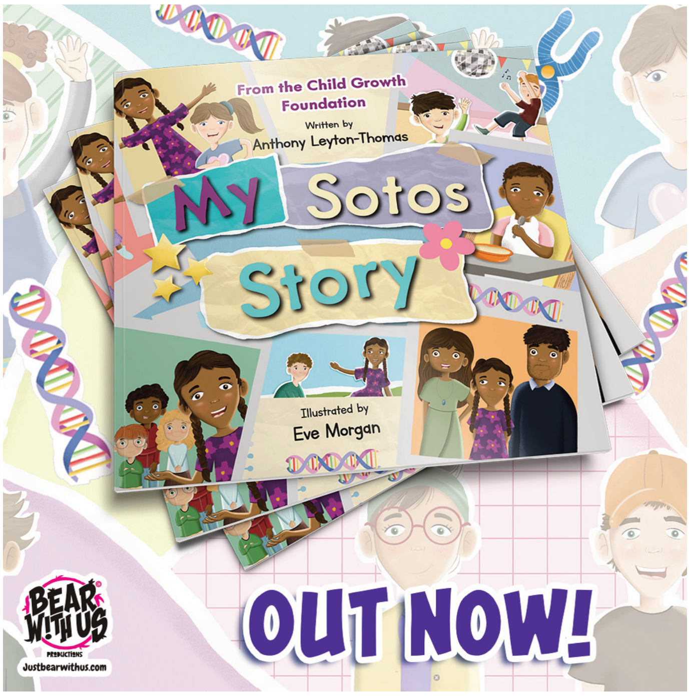
Join magnificent pup Max, brother Rex, sister Minnie, and their mum and dad in this heart-warming family story about Max's journey beginning injections to help him grow.

At the same age but different heights, Max and his twin brother Rex are getting ready to start school when tests reveal that Max's body isn't producing enough growth hormone. Perfect for reading together, this fun story helps children feel reassured and supported about starting injections, while giving parents and carers a gentle, child-friendly way to talk about treatment as a family.

childgrowthfoundation.org/max-book

All monies raised from the sales of our storybooks helps our charity's work making a difference wherever growth is a concern.

My Sotos Story



'Your genes are like instructions that tell your body what to do.

They set your height, what you look like – all the things that make you, you.'

With bright, colourful illustrations and fun rhymes, My Sotos Story is a book for children, families and anyone who wants to learn about the genetic condition Sotos syndrome – what it is, how it happens, and what it's like to live with.

childgrowthfoundation.org/my-sotos-story

SRS storybook fundraiser

After the launch of our first three storybooks, including a dedicated book for Sotos syndrome, we'd love to expand our storybook range to cover further growth conditions.

We're currently raising funds to be able to create a Silver-Russell syndrome (SRS) storybook, which will support our costs for the design and production of this new book to support SRS children and families.

If you'd like to make a donation to the SRS book fundraiser please visit here:

donate.giveasyoulive.com/campaign/srs-children-book

Trustee opportunities

We are seeking dedicated and passionate individuals to join our Board of Trustees.

As a trustee, you will have the opportunity to shape the direction of our charity, drive advancements for the children, young people, adults and families we support, and ensure that our strategy is delivered collaboratively with integrity, compassion and respect.

Joining the Board of Trustees at the CGF means being part of a team dedicated to making a positive and lasting difference wherever growth is a concern.

Our charity's work is focused on the support, understanding and management of rare growth conditions to improve the lives of children, young people, adults and families affected. As a trustee you will play a key role in guiding the strategic direction of the charity, working with fellow trustees to ensure compliance with legal and regulatory requirements and to maintain financial stability and drive growth.

We are particularly seeking trustees with skills, experience and/or knowledge in the following areas:

- Healthcare
- Clinical research
- HR
- Digital
- Fundraising
- Communications and/or Public Relations

We welcome applicants without prior trustee experience and will provide you with induction, training and ongoing support to help you navigate your trustee responsibilities. We are committed to building a diverse and inclusive Board of Trustees that reflects the communities we serve. We particularly welcome applications from women and from individuals from minoritised backgrounds, individuals who are disabled and/or who identify as a member of the LGBTQIA+ community.

How to apply

To apply for the position of trustee at the CGF, please submit a CV and covering letter (maximum two pages) outlining your interest in this trustee role and our charity, and any relevant skills, knowledge and/or experience, to Jeff Bolton, Chair of Trustees, at:
jeff.bolton@childgrowthfoundation.org

For full details please read our trustees opportunities document at:
childgrowthfoundation.org/trustee-opportunities

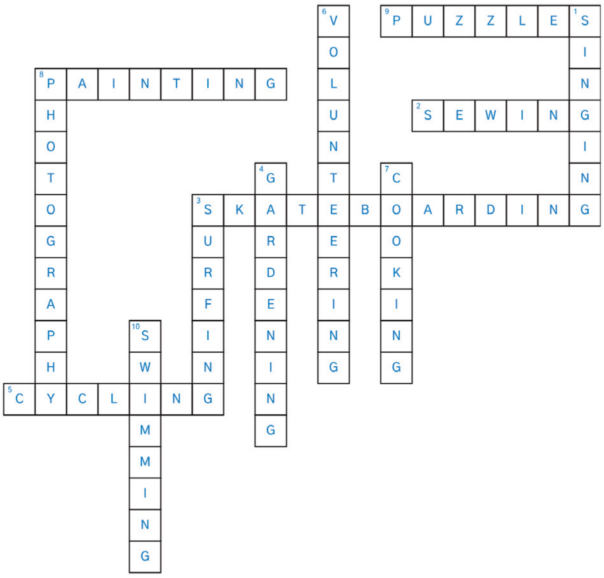
Hobbies crossword answers

Down:

1. Producing musical vocal sounds.
3. Riding ocean waves board.
4. Cultivating plants and flowers.
6. Helping others without pay.
7. Preparing food dishes.
8. Capturing images with camera.
10. Propelling body through water.

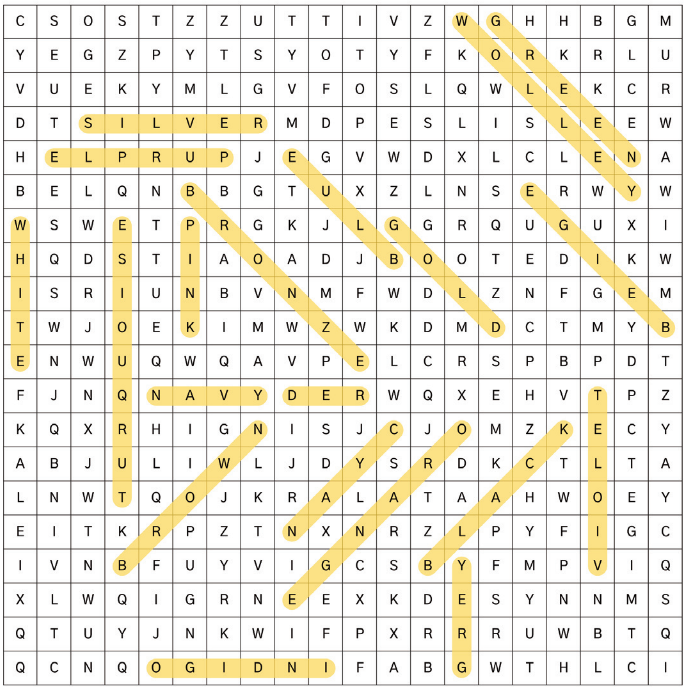
Across:

2. Stitching fabric with needle.
3. Riding on wheeled board.
5. Riding bicycles for sport.
8. Applying colour to surface.
9. Solving complex brain teasers.



Colours wordsearch answers

ORANGE	BLACK
TURQUOISE	BROWN
SILVER	CYAN
INDIGO	GREY
BRONZE	BEIGE
PURPLE	NAVY
GREEN	PINK
YELLOW	VIOLET
WHITE	GOLD
BLUE	RED



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X	L	W	Q	I	G	R	N	E	E	X	K	D	E	S	Y	N	N	M	S
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Joshua’s story

By Joshua’s mum, Lauren

Growth Hormone Deficiency (GHD)

Our son Joshua was diagnosed with GHD just before his 3rd birthday, almost a year to the day after his initial referral. The road to diagnosis felt slow at times and that often frustrated us, so we want to share our story in the hope that it helps someone else who feels they’ll never get there.

When Joshua was born, he measured the 50th percentile for length (height). Throughout his first year of life, he steadily dropped through the percentiles, reaching the 3rd percentile by his first birthday. His older brother at the same stage had been consistently around the 75th percentile, and both parents above the 80th, so we had immediate concerns regarding Joshua’s development. When he began to attend nursery, it became even more clear that he was lagging behind his peers in height.

As well as his height, Joshua had many of the other typical GHD symptoms. His teeth were late to erupt, and he had quite ‘cherubic’ features. Joshua was a poor sleeper, waking several times a night without an obvious reason, averaging maybe 5 wakes in a night. As a result, he was very tired in the day. His temperature regulation was poor, his lips would go blue even in a warm swimming pool, and he would sweat profusely on even a mild summer night. He also had a poor appetite, and had great difficulty controlling his emotions, even for a toddler.

By the time of his 2-year health visitor check-up, he was measuring at the 0.4th percentile in height, well below his mid-parental height at the 91st percentile. This, combined with his other symptoms, meant the GP was quick to refer us to a paediatrician.

The time between the initial referral and the first consultation was incredibly frustrating; we didn’t hear anything for 3 months and worried that something was wrong with the referral, or that Joshua had been overlooked. This was difficult as Joshua was continuing to display these symptoms, and we felt nothing was being done.

Once we had our first appointment booked with the consultant, I called the CGF to learn what to expect from the initial consultation and what might help us advocate effectively for Joshua. The CGF team were incredibly helpful. Using their knowledge and advice, we prepared carefully for the appointment, knew exactly what we wanted to say and to ask, and printed out all the evidence we might need.

We made sure we had a copy of his growth charts, the relevant NICE guidelines, a list of his symptoms, anything we could think of which would help his cause.

The first appointment was brilliant and the consultant took a full hour to understand our concerns. Now we were ‘in the system’, things accelerated. On the same day as the consult, bloods were taken, and Joshua was sent for a wrist x-ray. All results came back within range, except for mild anaemia, low IGF-1 and delayed bone age, pointing to a potential growth hormone issue. Due to this, the consultant ordered a GH Stim test (Arginine) to see if Joshua’s pituitary was able to produce GH.

In preparing for the stim test, we had read that it can be quite tough, particularly for younger children, as the fasting and the stimulant can make you feel terrible, and it is hard to explain the context to young children. But Joshua amazed us both by taking it in his stride. However, we found that the overnight fasting had exacerbated Joshua’s naturally low blood sugars, which measured low at the start of the test, and as fasting continues to the end of the test, we had one hungry boy by then!

The GH Stim test showed clearly that he wasn’t producing enough GH, and we were referred to a paediatric endocrinologist at another hospital. Again, we contacted the CGF and prepared as much as we could for the consultation. And again, we were very impressed with how thorough the initial consultation was. Further bloods were ordered, and Joshua was referred for eye tests, a head MRI, and a Short Synacthen test to rule out cortisol deficiency. A second GH stim test was also ordered; the GH Stim tests are not 100% reliable and there’s a risk of false positives, so two tests are required for a diagnosis. The Short Synacthen test is a similar format and fortunately they were able to perform both tests in one session. The eye tests were one each with optometry and ophthalmology, and not too different to regular eye tests.

In the meantime, Joshua was given iron supplements and provided with a blood glucose monitor which we used for several weeks. This for me was one of the hardest parts of the process, as it quickly became clear that Josh was experiencing hypoglycaemia most mornings before breakfast, and needed glycogel on several occasions due to dangerously low blood sugar levels. As we learned, GH has an important role in regulating blood sugars, so this is not unusual in young children with GHD. It was very worrying to know that Joshua’s body had been struggling in this way. From then on, we were hyper-aware of any symptoms that could indicate he was running low and tested him regularly.

The head MRI was daunting due to the need for small children to be administered General Anaesthetic. By this point, Joshua was beginning to lose patience with the many hospital visits and tests! The play specialist at the hospital really helped turn the situation around by giving us one of the masks that would soon be used to help put Josh to sleep, with no hose attached. We played a game of putting the mask over each of our faces and seeing how hard we could blow, which really helped prepare Joshua once it came to the real event. Other than a fire alarm going off during the scan, and the hospital being evacuated, all went to plan! Of all the tests, we were most nervous about these results, but we are thankful the MRI showed no abnormalities, and the second STIM test confirmed that Josh’s pituitary wasn’t producing enough GH. The eye tests and cortisol test all came back as normal.

When we received the call to say that Josh had GH deficiency and would be starting his treatment of daily injections within the month, it was such a huge relief. We had found the unknown to be the most difficult part of the process and finally knowing what we were facing felt like a huge weight had been lifted and we could now tackle this as a family, head-on. We selected an injection pen and hormone provider from the two offered by the NHS, had an opportunity to ask any questions about his treatment, and within a month we were administering injections daily.

We are now 9 months into growth hormone injections and have noticed a significant improvement in sleep and the shaky episodes have completely resolved which has been great to see. He's also grown 9cm and has just passed the 25th percentile for height! Joshua has amazed us throughout with his resilience and continues to do so, settling into the new norm of nightly injections. It's early days but we are hopeful that the improvements will continue.

If we could give any advice to other parents in this situation, it would be that knowledge is power! Gather all the information that you can prior to those initial consultations. Know the NICE guidelines for referral, know what questions to ask (give the CGF a call), and bring a list of all your concerns.

We have learnt that GH deficiency is so much more than 'just' height, but Joshua's short stature was the first sign that something was wrong. It's easy for that to be brushed off with well-meaning comments such as 'he's just a late bloomer' or 'he'll catch up', but we're so glad we trusted our instincts and got Josh in front of the right people to get him the diagnosis and the treatment he needs.

Image taken before starting growth hormone treatment. There's 19 months between Josh and his older brother, and at the time there was > 20cm difference between them in height

Image taken recently with his older brother

Update on Robert

By Robert's dad, Steve

Growth Hormone Deficiency (GHD)

As I write this it's hard to believe that almost the whole the year has gone.

Following on from my most recent update there was indeed a new arrival, on the 14th March, a baby brother for William who has been named Matthew. Had he waited a day Matthew would have had the same birthday as Robert on the Ides of March.

Emily is currently on maternity leave and Robert had a couple of weeks off but is now back at work with an extra mouth to feed. We have William on a Monday and it's incredible the advancement he makes week on week. Like many children he is like a sponge and has a prodigious memory. He knows nearly all of his Thomas trains and many of the makes of his toy cars, particularly Jaguars and Land/Range Rovers.

As expected work on the house has slowed down, purely because there isn't enough hours in the day plus tiredness due to a general lack of sleep. At least they have a plan for competion even if it keeps being pushed back. We are taking the family away on holiday in July just to give them a break for a few days so they can return invigorated. I'm not sure that will apply to Jackie & me.

Due to the family history of GHD doctors are monitoring both William & Matthew. Currently William is doing fine but it is too early to tell with Matthew. He has a hospital referral in a few weeks time where hopefully we will know more. He is certainly very bright and seems to know what is going on around him which is a definite plus.

Robert continues to impress at Cushman & Wakefield and he is really enjoying the work. His department goes from strength to strength and exceeds it's targets so he won't be moving on any time soon.

The next significant date later in the year will be Matthew's Christening where it will be great for the extended family to get together again.

Shop to make a difference wherever growth is a concern

Available through our online shop: childgrowthfoundation.org/shop

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