CGF News
Making a difference wherever growth is a concern

Autumn 2023

Child Growth Foundation
We are extremely grateful to everyone who has contributed to our newsletter and to all those who support our charity in so many different and valuable ways. Thank you!

Disclaimer:
The Child Growth Foundation 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 Child Growth Foundation 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 Child Growth Foundation.

Please consult your medical practitioner / health care professional for confirmation and/or advice.
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From our Chair

I hope you have all had a lovely summer. Time has really flown by since the last newsletter and it is hard to believe that we are three-quarters of the way through 2023. I am pleased to report, however, that the CGF has made great progress in developing and delivering its exciting plans that we outlined at the start of the year.

In addition to continuing to provide, and expand, support and guidance to families, whatever their growth concerns, the CGF has been focused on developing a campaign to drive and support a much-improved general public understanding of growth conditions, and a genuine appreciation of the need and potential to treat, manage and support them.

The CGF has been working closely with an expert communications agency to better understand the situation and challenges that families affected by growth conditions face, and some of you will have been interviewed by the agency, as part of the process. The CGF campaign, and response to our research, is currently being finalised and it is planned to roll it out in the next couple of months, and hopefully, at this year's convention, in October. Also, and in line with the aims of the campaign, the CGF has been busy expanding our range of educational materials and are continuing to investigate and engage in more digital opportunities.

The CGF is very aware of the challenges that families face in getting their child referred by their GP, to the appropriate expert; we know too well that it is common for families' growth concerns to be dismissed or referral of their child to a specialist to be delayed. Our discussions with GP organisations revealed that GPs have identified growth conditions as one of their priority educational needs.

The CGF, therefore, is now developing a programme of educational support for GPs, and other first-line healthcare workers, to improve their knowledge and understanding of growth conditions, and provide them with expert guidance for when and how to refer a child with a suspected growth condition to the appropriate specialist.

The first part of our GP programme will be a growth condition online seminar, which will be presented by growth experts and hosted on a centralised learning hub for GPs and the primary care community. It is anticipated that the webinar will be held as part of a rare disease event, towards the end of the year.
Both the CGF’s community and GP campaigns are intended to contribute to the timely and optimal and specialist treatment and management for all growth conditions. The CGF is determined to make a positive difference for families affected by all the growth conditions that we support.

As part of that planned expanded support for families, I am pleased to announce the CGF’s appointment of a new, part-time Paediatric Endocrine Nurse Specialist, Lisa Hill. Lisa brings significant expertise and experience to the CGF team. A key part of Lisa’s role, together with Sally our Growth Nurse Specialist, will be able to provide confidential support to families affected by growth conditions, offering medical information and guidance to help discussions between patients and their medical teams.

Also, and very much as part of the CGF’s commitment to support to families affected by growth conditions, we hope we will have the opportunity to meet you at the CGF’s forthcoming annual convention in October.

I am pleased to confirm that this year’s expanded convention programme has been developed in line with your feedback and requests. As usual, the convention will be an opportunity to meet and ask questions of the growth experts. It will also include expert presentations on identified key topics, and opportunities for facilitated experience sharing between families.

There will be a session to inform families on how to get the most out of their physician consultations, and a plenary, expert presentation and discussion, on the emotional impact of growth disorders on all the members of the affected family. Also, as always, there will plenty of time for socialising and having fun. I hope you can attend, and it would be great to see you there.

I look forward to meeting with many of you very soon.

Best wishes to all

Jeff Bolton

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Child Growth Foundation AGM

Our AGM will be taking place at 9.30am on Saturday 7th October at Delta Hotels Warwick. Join Jeff, Vice Chair Jessica Watts, Treasurer Steve George and our Board of Trustees to hear important reflections and updates from the CGF, as we report on the past year and look ahead to our upcoming plans in the child growth community.

If you have any queries about our AGM please contact info@childgrowthfoundation.org.
It will soon be one year since I joined the CGF...how quickly that year has gone! I’ve loved meeting so many individuals, groups, charities and other organisations over this past year.

From working with our growing team of expert Medical Advisors and connecting with teams at other passionate charities, to speaking with inspiring fundraisers and dedicated volunteers, no day is the same as the next. One thing that does stay constant though is a shared common goal of supporting both those with a diagnosis and those seeking a diagnosis, where and when it’s needed most.

We’ve recently joined the Disabled Children’s Partnership (DCP), a coalition of over 100 organisations campaigning for improved health and social care for disabled children, young people and their families. Through partnerships like the DCP we have an increased platform to talk about the challenges many of you are facing. It’s one of the many steps we’re taking to raise the voice of children and families in the growth community.

We’ve had really exciting developments internally, including Lisa joining the charity and growing our nursing team, and there’s been there’s been lots of work behind the scenes planning convention. I can’t wait to meet so many of you there in October!

The CGF also won Prestige Awards Central England Children’s Support Non-Profit Organisation of the Year, where Sally and Laura collected the award on behalf of the charity. We’re delighted to have won and are so grateful to our team of staff, trustees, Medical Advisors, volunteers, supporters, fundraisers, donors and many more who make our work possible to support children, adults and families wherever growth is a concern 💙💙💙
Update from Sally

Growth Nurse Specialist
sally.majid@childgrowthfoundation.org

The past six months have flown by, and I’m delighted Lisa Hill has joined the CGF team. In preparation for Lisa starting, I’ve been looking at our Support Line processes and reviewing the ways in which we provide support to families who call and email us.

Quite often callers contact us to share their concerns and worries and I feel incredibly privileged to be able to spend time talking through their challenges and supporting them in accessing the answers and care they deserve. We have become a member of the organisation Helplines Partnership who support charities big and small who run a phoneline service. Lisa and I plan to attend one of their training courses later in the year and we are moving forward to ensure we reach even more families, continuing to offer support both before and after diagnosis.

At the end of March, I attended an information day at the QE Hospital in Birmingham. It was interesting to see how things work in the ‘adult’ world and how other charities support patients and members.

Families connecting through their shared experiences is an important aspect of support, and we are always considering how we can facilitate and connect more families with each other. Currently we are working on setting up a Hypopituitarism peer support programme in Northern Ireland. We have a wonderful volunteer in the area, who is working with us to set up the first meeting. So, watch this space as we look to create similar groups for all our conditions in different locations. If you would like to volunteer for us and set something up locally to you or virtually with a condition you’re connected to please don’t hesitate to get in touch at volunteer@childgrowthfoundation.org.

The CGF team have attended a few events in the last six months, spreading awareness of growth conditions and providing information about the CGF and the work we do. Catriona, Laura and I spent three days between us at the Society for Endocrinology event in Birmingham. Along with meeting healthcare professionals we met with other organisations and charities, including Addison’s Disease Self-Help Group (pictured with me here).

In May and Laura and I represented the CGF at the Prestige Awards where we won Central England Children’s Support NPO (Non-Profit Organisation) of the Year.

We have lots of exciting plans for this year’s convention, and I’m really looking forward to seeing everyone there.
Hello from Lisa

Paediatric Endocrine Nurse Specialist
lisa.hill@childgrowthfoundation.org

Hi everyone, I’m Lisa and I’m really excited to have joined the CGF as Paediatric Endocrine Nurse Specialist (PENS). There are so many exciting things I have heard about and I’m really looking forward to coming to the convention this year.

I will be working with the CGF part time whilst continuing with my post of PENS at the Royal Derby Hospital. I have always worked with children and young people both in nursing and, prior to that, in education. My first job was as a support worker in a residential special school for children with autism and moderate to severe learning difficulties. It was at that point I knew that working with youngsters and their families was the career for me!

Away from work, I enjoy spending time with my husband, two daughters and our sprocker called Molly. If I’m not ferrying the kids to and from their various hobbies I will be running around a dog agility field trying to tempt Molly to stop chasing the butterflies and actually do the jumps and weaves she’s supposed to be doing! I also like to try lots of different craft - my latest attempt was a needle felted hedgehog (pictured below) which, despite my best efforts, wasn’t quite at the standard of the instructions I was following. I think I will stick to crocheting in the future!

I look forward to speaking to/meeting you all. Please do get in touch if there’s anything you would like to share or I can help with.

See you all soon

Lisa

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#MemoryWalk
We're so excited for this special event to return 6th-8th October, and the CGF team can’t wait to see so many of you there. With the event being held in October we have set the spooktacular theme of Halloween!

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

Online booking is open with places starting at £15 for Saturday daytime, or make a weekend of it and join our Friday and Saturday evening activities too at Delta Hotels Warwick. Plus new for this year we'll have bookable slots with our nursing team on the Sunday morning.

With talks on conditions themselves, the emotional impact of growth conditions, tips for appointments and more, we've got a great event lined up for learning, socialising and sharing.

Book to join us at www.childgrowthfoundation.org/convention. To request an offline version of the booking form or for any other queries about the event please email convention@childgrowthfoundation.org.

**Prizes request!**

We will be holding a raffle and tombola at convention, as well as having our CGF stall selling goodies. If you have any prizes that you would like to donate, please let us know or bring them along with you. Please note that we are only able to accept new items.
At the Child Growth Foundation we are privileged to have the following health professionals advise and support us with the work that we do. Our experts help create the information and booklets you see on our website and are regular speakers at our annual convention.

If you have queries regarding you or your child’s treatment we recommend you speak to your consultant in the first instance. If you need further advice please contact our Support Line (details on page 40). For any queries we’re unable to answer we will seek an expert opinion on your behalf.
As you might remember from previous newsletters in 2020 we created the National British Society for Paediatric Endocrinology and Diabetes (BSPED) Growth Disorders Special Interest Group (GD-SIG).

The ‘mission’ of this group is to improve the recognition, diagnosis and management of growth disorders in the UK and to coordinate research and education in this field.

Our hope is to provide a focal point for clinical staff, patients and families nationally and put growth disorders on a level footing with the other major endocrine disorders affecting children.

Membership is growing and we currently have 20 members with wide representation from around the UK including CGF Growth Nurse Specialis Sally Majid, CGF Chair Jeff Bolton, and several individuals well known to the CGF; Professors Helen Storr and Justin Davies, Dr Renuka Dias and Jenny Child.
Since the last newsletter, two important national position statements have been completed by the group. One has been adopted by the BSPED and uploaded to the official website, the other is currently under review by the BSPED Clinical Committee:

‘Growth hormone therapy in Silver-Russell Syndrome (SRS) between 2 and 4 years of age’

‘Clinical Standards for GH Treatment of Growth Disorders in Childhood and Adolescence excluding GHD’.

The aim of the first document is to endorse the international consensus SRS guidelines that growth hormone treatment should be made available for SRS children from the age of two years to increase height and to optimise body composition. GH therapy should also be made available earlier if there are problems with low blood sugar levels (hypoglycaemia).

The second, followed the finalisation of the ‘Clinical Standards for GH treatment of GH deficiency (GHD) in Childhood and Adolescence’ which was published on the BSPED website last year:


The new document highlights our recommendations for the other conditions licensed / treated by growth hormone. We hope we can share these with you later this year.

With these completed, we are now working on several new projects. These include:

• A survey of paediatricians / paediatric endocrinologists to understand the variability of growth charts across the UK. This will be conducted with the help of members of the BSPED and The Royal College of Paediatrics and Child Health (RCPCH).
• Updating the clinical Standards document for IGF-1 treatment.
• Writing a new position statement which will provide guidance around prescribing, starting and monitoring the new long-acting growth hormone therapy for growth hormone deficiency.

Our next meeting is scheduled on 3rd November 2023. If you would like to get in touch about the group or would like to put forward some ideas for discussion, please contact Helen at h.l.storr@qmul.ac.uk or Jeff at jeff.bolton@childgrowthfoundation.org by email.

Professor Helen Storr, Chair and Coordinator of the BSPED GD-SIG
Professor Justin Davies, Deputy Chair of the BSPED GD-SIG
Understanding the link between child growth and development

Dr Joe Freer, NIHR In-Practice Fellow, Barts and The London School of Medicine, Queen Mary University of London (QMUL)

Children’s growth and development are closely connected, but the links between them are complex. Over the past three decades, there has been mounting evidence from low and middle income countries that children growing up in poverty are not meeting their potential for growth and development, including cognitive, speech and language, motor and social-emotional abilities.

Unearthing new insights with the Millennium Cohort study

There has been little recent research in this area in high-income countries such as the United Kingdom. As part of our research into associations between growth and development (see our other article in this newsletter), we recently looked at data from children participating in the Millennium Cohort Study (MCS). The MCS, also known as ‘Child of the New Century,’ has been following around 19,000 children from birth at the turn of the century, through school and into adulthood. We have published our findings in the journal BMC Medicine.

Association between short stature and language development

We found that children in this cohort who had short stature at age three years had poorer performance in language testing from ages three to 11 years. Because shorter stature can be a marker of deprivation and other factors, we used statistical tests to remove the effect of these factors, but found that short stature was still - independently - associated with poorer language development.

Some children who have short stature in early life grow faster at a later point in childhood. We looked at children who had experienced this ‘catch-up’ growth in height, and found that they had better language test scores than children who still had short stature at age five years, but had lower language attainment compared to children who never had short stature.

These results form a useful part of the body of research looking at associations between growth and development.
However, it is possible that factors that were not included in the original dataset, and which we therefore could not examine in our analysis, truly explain the link we found between short stature and poorer language development. For this reason, growth may just be a ‘marker’ of these factors and of poorer language development, rather than the ‘cause.’

Implications and future directions

This research suggests that short stature at age three years or younger could potentially be used to predict future risk of cognitive or educational problems and be used to identify children who would benefit from further assessment and early intervention. Further research is required to investigate this further.

If you would like to get in touch about this study or would like to input into our work, please contact Joe at j.freer@qmul.ac.uk or Helen at h.l.storr@qmul.ac.uk by email.

Child growth and development in East London study: an update

Dr Joanna Orr, Postdoctoral researcher, Queen Mary University London (QMUL)

The Child Growth and Development in East London (CGEL) study is currently being rolled out in Tower Hamlets. The study, conducted by our team at QMUL, is assessing the feasibility and acceptability of the use of growth screening in pre-school aged children. Early results show that screening children at age two as part of the Healthy Child Programme run by health visitors would be possible and likely beneficial to the child population.

The study has been running since May 2022 and has so far recruited over 450 children. Study participation involves the child having their standard two-to-two-and-a-half-year review with the study health visitor. The health visitor then collects some extra information about the child, their health, their circumstances, and the heights of the parents.
The child’s and the parents’ heights are then used to calculate a standardised height score for the child, and a measure of how close each child is to their expected height based on their parental heights.

Children who are below expected levels on either of these measures are flagged for referral to a specialist growth clinic. A follow-up visit will also allow us to look at children’s growth over time. Several children who have been identified by this screening have already been seen at Professor Helen Storr’s growth clinic. Our early experience is that this could have a positive impact on children living with growth-affecting conditions who have yet to receive a diagnosis.

To implement such a screening programme nationwide would require both healthcare providers and families to be on board. Because of this, the study has also collected qualitative focus group data on parents and health visitors’ views on growth screening. We found that parents would like more formal screening programmes for their children and would appreciate more clarity in the roles and what can be expected from the various healthcare professionals involved in their child’s care.

Health visitors were interested in new tools to help assess and refer children. Both parents and health visitors stressed the importance of properly resourcing any screening programme, so that children and families who were found to need support could access it.

Finally, we are also interested in the link between growth and early child development. We are collecting data from the standard developmental test used to assess children at this age (Ages and Stages Questionnaire – ASQ).

We are also conducting more detailed developmental assessments on a subsection of our participants. This data will help us understand the association between growth and development. We have explored this question before, as discussed in the previous piece in this newsletter by Dr Joe Freer.

Growth in childhood is becoming increasingly recognised as a marker for a child’s health and environment. Recent reports of the UK’s declining position in the global height rankings for five year olds (NCD Risk Factors Collaboration; https://ncdrisc.org/height-mean-ranking.html) have raised questions on what the causes of this decline is, and whether austerity could be to blame.

Our group previously found that short stature in children was highly associated with deprivation, and that the most deprived areas of the country had higher rates of short stature (including East London). Whether these inequalities are also linked to poorer access to healthcare, diagnosis and treatment of growth-affecting conditions is an important future question.

If you would like to get in touch about this study or would like to input into our work, please contact Joanna at joanna.orr@qmul.ac.uk or Helen at h.l.storr@qmul.ac.uk by email.
Central Precocious Puberty (CPP) live webinar series

CPP is a recognizable disorder which, with knowledge, skill and experience, can be managed effectively. The webinar series will inform paediatricians and paediatric endocrinologists how to recognise patients with CPP, and how to identify CPP amongst the wide variations of pubertal development (Bräuner, 2020).

**Learning Objectives**

1. Demonstrate awareness and differentially diagnose CPP within the range of variations of growth and puberty in paediatric endocrine practice.
2. Recognise a patient with progressive CPP who requires urgent diagnosis and therapy.
3. Choose and initiate GnRHa therapy in CPP.

**Target audience**

Paediatricians, endocrinologists and clinicians involved in growth management.

**Free registration**

Scan the QR code to the right to open the booking page.
Mental Health Resource Project

Developing a mental health resource for young people living with an undergrowth condition

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

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

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

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

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

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

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

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

To receive a copy of the questionnaire and the supporting information pack including a Q&A for families, please contact Catriona at 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.
StratifID is the latest study by the Southampton Imprinting Research team and is funded by the Medical Research Council. The study aims to understand how a type of genetic change (multi-locus imprinting disturbance) affects growth, development and health in children with Silver-Russell Syndrome (SRS) and other imprinting disorders.

We will stratify people with SRS, and other imprinting disorders, according to whether or not this genetic change is present and we will investigate the health consequences. This information will help medical teams to predict who will require specific interventions; medical therapy, nutrition, educational support etc, so we can optimise health in people with SRS over their lifetime. This could lead to a step change in personalised medicine for people with SRS.

**Background**

Our bodies are formed using the genetic ‘instruction book’ made of DNA, which we inherit from our parents. From our eyes to our toenails, every cell in our bodies contains the same DNA – but every cell uses it differently. DNA changes can cause genetic disorders that make people unwell from their birth. But some rare disorders aren’t caused by changes in DNA itself, but in how that DNA is used; these are called imprinting disorders.

SRS is an imprinting disorder that happens when DNA that should be used from only one parent’s instructions, is instead read from both parents’ copies, or neither. People with SRS have reduced growth both before and after birth, so they need a care plan that fits them and helps them to thrive.

But families and doctors know that one plan doesn’t fit all children with SRS; children vary in their growth, appetite, response to Growth Hormone, and many other ways, and we suspect that imprinting disturbances, more complex than currently recognised, underlie part of this variation.

**What the team will do**

We will recruit children with molecularly diagnosed SRS, and another imprinting disorder Beckwith-Wiedemann Syndrome. For each child we will create a detailed picture of their growth and development, and precisely map out the changes in how their DNA is used, and measure their metabolism using state-of-the-art tests (in a simple pee sample!). We will find patterns that link their imprinting disturbance with their clinical progress. If we stratify imprinting disturbances in this way, we can predict what management will be best for different people.
If you want to know more

The team behind this study would love to hear from families who have a child (ideally under ten years old) with molecularly diagnosed imprinting disturbances. The study will run for three years from September 2023. Most, but not all, children with molecular SRS will be eligible for the study. If you would like to learn more, please email genetics.ops@uhs.nhs.uk with the emailed subject ‘StratifID’.

In the news...

One of the major deficits in understanding normal and abnormal hormone secretion has been our lack of ability to measure hormone levels across the whole day in people in their normal home and work environments. Endocrinologists have tried to get over this by devising tests that either stimulate or inhibit hormone secretion, but none of these tests is as good as knowing what happens in any one individual across the day—including during the critical time when they are asleep.

Professor Lightman and his team at the University of Bristol have now designed and manufactured a novel device that can do just that—measure your hormone levels at home over the whole day. This breakthrough has already been tested on 214 people in whom all their cortisol related hormones have been measured.

Read more at www.bbc.co.uk/news/uk-england-bristol-65961378

Share your news, updates and insights

If you work in a medical, healthcare or research setting and have news, updates or insights to share that would be of benefit to children, adults and families in the growth community, please get in touch at news@childgrowthfoundation.org.

Along with this bi-annual newsletter, we share key news on our website, on our social media channels and in our e-newsletters.
GENROC study opens for recruitment in the UK

Improving the treatment for children with GENetic Rare disease: Observational Cohort (GENROC) study
Dr Karen Low

WHAT ARE WE?

GENROC is a research study involving researchers from the University of Bristol and clinical geneticists across the UK. We are interested in how rare genetic syndromes affect children’s growth and development and their families. We want to work with parents to improve the information available to everyone about these conditions.

Parents will be asked to complete online questions. Children will not be required to do anything.
This study has been set up by Dr Karen Low, a consultant clinical geneticist based in Bristol. Dr Low is particularly interested in genetic conditions that cause children to have developmental delay, intellectual disability and/or autism.

She has conducted research into a number of syndromes particularly including KBG Syndrome, PUF60 related syndrome, and HUWE1 related syndrome. Dr Low is a member of the KBG foundation scientific advisory board, has organised a UK KBG family day in association with Unique and has written 4 of the Unique patient information leaflets.

In her work in these syndromes Dr Low has seen how difficult it can be for families when not enough is known about their child's genetic condition and how this can impact on their clinical care. Gene specific growth information is an area that is often lacking in many of these syndromes.

**What is GENROC aiming to do?**

The idea behind GENROC is to improve the amount that is known about a number of rare genetic syndromes. By understanding the syndromes better, doctors will know what is expected for a child with that particular condition and will therefore have a better idea about how to treat them and whether or not certain investigations might be needed. In particular, the hope is that by doing so the team will produce useful information for making clinical decisions such as gene specific growth curves.

**How are they going to do it?**

The GENROC team believe that parents of children with genetic syndromes know a lot about their child’s condition – often more than most of the child’s doctors! GENROC also recognises that many of the social media groups generate a lot of very useful data about these syndromes.

The team will collect data from different sources which will include from parents via online questionnaire. This will take place at the point of joining the study and then later as well allowing more insight in to how children are affected as they grow (rarely investigated in genetics research). The child’s genetics doctor will also be asked to send some information.

The team will be looking at some additional interesting areas including whether websites and social media data can help and whether machine learning and data linkage might be possible and useful in improving clinical care in rare syndromes.

**How can we take part?**

At present the study team are looking for families with changes in specific genes only. Please see the following images to see if your child is eligible for GENROC. Eligibility criteria and the full parent information leaflet is available at www.childgrowthfoundation.org/genroc-study. Any questions can be directed to genroc-study@bristol.ac.uk.
YOUR CHILD IS ELIGIBLE IF...

- They have intellectual disability / developmental delay / autism
- They have a causative change in one of the genes shown (see next image)
- Parents or guardians are willing and able to give informed consent for participation in the study and can complete online questions
- They are male or female, aged 6 months-15 years
- Your child lives in the UK
GHD Reversal research study for children and young people whose Growth Hormone Deficiency (GHD) has reversed

The GHD Reversal study is investigating whether young people make enough growth hormone on their own as they enter puberty. This could stop the need for daily injections of growth hormone. All children in the study will be very carefully monitored.

To get more information you can contact your own doctor directly or contact the GHD Reversal Trial Office on the below details.

GHD Reversal Trial Office, Birmingham Clinical Trials Unit, University of Birmingham, B15 2TT
Email: GHDReversal@trials.bham.ac.uk
Website: www.birmingham.ac.uk/GHD

UNFORTUNATELY YOUR CHILD IS NOT ELIGIBLE IF...

- The genetic change is a VUS or uncertain
- They have more than one genetic change
- The genetic change is in a gene not in the list
- The genetic change is a chromosome microdeletion or duplication
- The genetic change was found by the DDD study
Behavioural and Emotional Outcomes in Neurodevelopmental Disorders (BEOND)

What is the study about?

The team behind the study are wanting to collect information about changes in behaviour, emotion, physical and mental health for people with genetic syndromes, neurodevelopmental disorders and intellectual disabilities. This is so they can understand the impact of these experiences and hopefully offer better ideas of support.

Who can take part?

You can take part if you are a parent or carer of an individual diagnosed with either a genetic syndrome, autism and/or an intellectual disability. The person you care for must be at least one year old.

What will they ask me?

You can take part if you are a parent or carer of an individual diagnosed with either a genetic syndrome, autism and/or an intellectual disability. The person you care for must be at least one year old.
Volunteers Needed: Research Study on parental experiences of the transition from paediatric to adult care services for young adults diagnosed with a growth hormone disorder, UK

Are you a parent with a young adult diagnosed with a growth hormone disorder that is currently transitioning, or has transitioned from paediatric to adult care services within the past five years? (UK only)

Inclusion criteria
- Live in the UK
- Child/young adult with a GH disorder
- Transitioned from paediatric to adult care services within the past five years
- Willing to be interviewed online

Participation involves
- Being interviewed online at a suitable time (30min)
- Discussing your experience
- Data to be stored securely
- Personal details (including names) will be anonymised

Aims of the study
To explore parental experiences of transitioning from paediatric to adult care services within growth hormone disorders. To investigate common themes that may form advice on how to support parents through this significant life event and promote an optimal transition programme.

Purpose and background
Laura Foot is a member of the Child Growth Foundation and is a parent who has a child diagnosed with Growth Hormone Deficiency. She is a mature Psychology student at Arden University.

To volunteer please email STU96284@ardenuniversity.ac.uk
Thank you
Fantastic fundraising!

River Luders raised over £300 through his half marathon challenge

Rob George raised over £1000 in the Race to the Stones Ultra Marathon

Liverpool FC Women Supporters Club raised £180 for the CGF

Lynn Leonard raised over £200 in the Loch Lomond 10k

Denise Gregory and daughter Isabella raised over £1000 for Denise’s 40th birthday
There comes a moment in a marathon, maybe around 18 miles in, when it all gets a bit much. Your legs are leaden, your brain is sluggish, bits of you have started to hurt, and the idea of continuing running for another eight (point two!) miles seems almost comically unlikely. On 23 April this year – my second London Marathon for the CGF in as many years – I felt this particularly acutely. Panic began to set in. ‘What if I can’t finish it? Shall I just... stop, now, and go have an ice cream instead?’

If I weren’t running for a charity, I might have given up, had my ice cream. But when you have hundreds of pounds in sponsorship jingling around in your justgiving coffers, you can’t just give up, can you? You have a responsibility to earn your donations, to finish the race. I couldn’t let everyone down, no matter how much I wanted a Solero.

So if the only option is to keep going, how do you do that? For me, halfway between miles 18 and 19, somewhere between Canary Wharf and Blackwall, the best way to tackle it is to break it down mentally. Miles 18.5 to 21 is section A, 21 to 23 section B, 23 to 24 section C, and so on, getting a little shorter each time all the way to that last point two. That way, instead of one apparently impossible goal, you have a series of little victories to strive for. It’s still hard, of course, but each one you achieve bolsters you a little bit more, pushes you a little bit further towards that finish line – which suddenly doesn’t seem quite such a distant prospect.

It was around mile 22 when I started to see the parallel between this approach to tackling a marathon and charity fundraising. As an individual fundraiser, unless you’re Captain Tom, it’s unlikely that you’ll raise a fraction of what a charity like the CGF needs to keep running and helping people. Sometimes it might seem as though there’s little point in you bothering. But the thing is, collectively, once your contribution has been added to those of others, the figures start to add up in a really quite extraordinary way. Every contribution, however small, matters enormously. The smallest section of my marathon break-down was ‘section F’ – that final 0.2 mile stretch to end outside Buckingham Palace. It may not have been that far to run in the grand scheme of things, but it was what got me over the finish line. When lots of little efforts are added together, we can really go the distance.

To learn more about fundraising for the CGF visit childgrowthfoundation.org/fundraising.
Join our weekly lottery from £1 a week and be in with a chance to win £25,000!

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

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

If you need help with joining our lottery please call Unity on 0370 050 9240.

We've been supporting children and families for over 45 years.

We need to raise £45,000 in fundraising and donations over the next year.

Can you help us reach our goal?
We’re registered with Making A Difference Cards, an online card platform where you can order individual printed cards, packs of cards and e-cards too: https://gb.makingadifference.cards/supporting/child-growth-foundation

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

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

Virtual London Marathon

If you are interested in a 2024 Virtual London Marathon place we’d love to hear from you at fundraising@childgrowthfoundation.org.
VIRTUAL BALLOON RACE

Join this eco-friendly event raising funds as part of Children’s Growth Awareness Week.

Buy and personalise your own balloon at £3 each before the balloons begin their digital race at **midday on 7th September**.

Balloons will race until **midday on 14th September**, raising funds to make a difference wherever growth is a concern.

Top three winning balloons will each win a prize. **Top prize is a cream team for two hamper!**

To buy your balloons visit [childgrowthfoundation.org/virtual-balloon-race](http://childgrowthfoundation.org/virtual-balloon-race) or use the QR code to the right before **midday on 7th September**.
Thank you so much to our members for continuing to pay the annual subscription. The support you provide through both new or continued membership helps us deliver invaluable services to families affected by rare growth conditions. There are a number of ways you can pay for your membership:

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

- **By card**
  Via our website: www.childgrowthfoundation.org/membership

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

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

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

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

- A printed copy of this twice-yearly newsletter delivered to your door
- Member-only benefits for convention including early bird booking and member goody bag
- Access to our members-only area of our website

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

Membership costs just £25 a year to UK residents and £30 for those living overseas. The fee is the same for an individual or a whole family. Find out more at: www.childgrowthfoundation.org/membership
Update on Emily
By Emily’s mum, Rachel

Silver-Russell Syndrome

It has been a few newsletters since I included an update on Emily, so here’s a little catch up.

Em is now 21 years old and getting on with her life, studying at Leeds Uni where she has just finished a BSc in Biology and is hoping to continue with an MSc in Biodiversity & Conservation next year.

We do not tend to think too much about RSS anymore. Emily looks after her own health, which includes regular check-ups with the GP for mental and physical health issues. She’s awaiting a referral for ADHD diagnosis, although she is in for a long wait for that one.

For those of you who are new to the CGF and might now know so much about Emily, here’s a very quick overview - she has RSS 11p15 LOM, was 3lbs 3oz at birth (35wks), weighed 11lbs aged one, 13lbs age 2 and 16lbs age three years. She was born under 0.4th centile for length and gradually made her own way up to 4th centile by age four years.

Treatment with GHT between ages nine to 14 years as she progressed through puberty helped bring about a fantastic final height of 5ft 1.5”. We’re a tall family, so Em’s genetic potential was around 75th centile, but making it to the 25th centile is great – she has no issues with driving, finding clothes or living a full and very active life. She has a full history of eating issues, gut dysmotility, reflux, hyper mobility, hypo issues and delayed physical milestones, lots of orthodontic work and orthotics to help with small (size 13/EUR 32) high arched feet.

Her later teen years weren’t so great with multiple mental health issues, but Emily still persevered and attained well deserved GCSEs and A levels in Biology, Chemistry and Geography, which led her to study Biology at university. Emily is way more interested in the plant and insect side of Biology, not so much the human elements – and various activities at university have involved helping bees, and conducting bat surveys.

As I write this, she is currently in Mexico for a four week Ecology Research Assistant role with Opwall – the photo above is from the day she left. Dan, Emily, Fran (who has just finished her GCSEs) and I will be attending the CGF convention in October and look forward to catching up with lots of you there!
Welcome to my September 2023 update.

Rober & Emily are adjusting to life as parents. William is progressing and we are looking after him on a Friday. Each week he seems to be doing more and he will be walking soon.

Robert has recently changed jobs and he is now working in commercial lease consultancy at Knight Frank in their Birmingham office. It is early days but he seems happy that he has made the move. His old employer has said they would have him back any time which is nice to know.

William is still being carefully monitored by the local hospital but as time goes on it seems less and less likely that he has inherited GHD.

Work continues on their property albeit slowly as they are both back at work now. The ultimate intention is to go off grid and I don’t doubt they will succeed.

You may have seen that Robert has completed a sponsored run called Race to the Stones. At the time of writing he has raised over £1k plus Gift Aid for the CGF.

I attach a couple of photos of the event plus an obligatory one of William.
Update on James

By James’ mum, Laura

Silver-Russell Syndrome

Lights, camera, action!

As I’m writing this update, James is just coming to the end of his first round of mocks! He has more in November and in early 2024, so he has more opportunities to be ready for his GCSEs. We’ve been in lots of discussions with the SENCO and teachers about access arrangements, so this first round has been a good way to explore if the arrangements are working for James.

At the moment he is having extra time, a scribe and breaks for snacks. He did his Food Tech practical a few weeks back and for a child who had a GJ tube until he was nine years old, it was incredible to see how well he did in making three courses, including jointing a chicken and making pastry! He was struggling to keep up with the oral side of Spanish, which isn’t a surprise considering the challenges he has with his day to day speech, so we decided it would be best to drop that. This created some space in his timetable for extra maths and science, so it’s had a positive impact.

Talking about speech, James is finally (fingers crossed) going to get some specialist ASD speech and language therapy at school. I had a long conversation with the therapist, who is already supporting two children with ASD at James’ school, and she has just met James at school for an assessment. We should then be ready to kick everything off on his return to school in September. You will probably not be surprised to know that I have been continually fighting for SALT since James started at secondary school.

We thought we had a breakthrough when he was finally reassessed in February 21 and diagnosed with a developmental language disorder, but after a couple of therapy sessions, technology/connection problems, the pandemic and the therapist’s illness thwarted his sessions and he was then discharged AGAIN. Since James’ ASD diagnosis in December 22, the SENCO has been pushing the local Communications and Language Team to get the support and to have it added to his EHCP. It’s still not signed off, but I’m hopeful we’re getting there.

During June we attended two ASD workshops at Great Ormond Street, called the PEGASUS programme. James spent some time with other children with ASD and psychologists and we met other parents and learnt lots about ASD.

They explored and celebrated their differences and strengths and James seemed to enjoy being part of the sessions and to meet other children. I still feel like I have lots more to learn to do the best for James and to get him the right support.
Like so many families, we’ve been experiencing severe problems with the national supply shortage of Norditropin. I’ve lost count of the amount of phone calls I made and emails sent to Alcura and to the endocrine nurses – who I have to say were very patient and supportive as it was not something they could control – but we were lucky and never ran out completely, although we did have to reduce James’ dose a few times.

We decided to go with Genotropin and now have a new device, stock delivered, had our training and are ready to start using it all in the next few days. It seems more complicated but hoping we’ll soon get used to it all and just grateful we now have stock again.

In our last update I mentioned James had a small speaking part in the school production of Bugsy Malone. Well it was more than a small part and he was the character Doodle. He was AMAZING!

His American accent was brilliant – he was so clear and so confident. He also had lots of custard pies in his face, which I thought he would hate but it was in the line of a good performance so he went with it! I felt so incredibly proud of him. Not just for the show itself, but for sticking with it, signing up and auditioning on his own steam, all of the rehearsals and learning the lines.

He’s also joined a small theatre group called Playmakers which is linked to the local theatre and performed this weekend in the Hat Fair in Winchester.

Hat Fair is a weekend of all kinds of street performers, and he was a magician in the production they all wrote themselves called ‘Hat Fair Goes Wrong!’ . He had a lot of lines to learn and did another great performance.

It’s felt a long journey to get to this point, but all of a sudden he has a few weeks left and in September will be entering is final year at secondary school and taking his GCSEs.

We’re starting to explore colleges and what’s next for James. He really likes his drama, so maybe something with this but lots to look into over the next few months.

If you have any questions about James and our journey, please do get in contact. Enjoy your autumn, and I look forward to seeing many of you at convention in October.
Bob Brady’s story

My Name is Bob Brady, and I am from Ireland.

In 1991 I was diagnosed with a craniopharyngioma tumour on the Pituitary Gland, when I was eleven years old.

I had some symptoms but they developed over time, which delayed diagnosis. These symptoms included, headaches, vision loss, Diabetes Insipidus, small stature, low energy levels etc.

In May 1992 I had surgery, a craniotomy, to remove the tumour. Due to the size of the tumour, my Pituitary Gland was also removed. As a result, I now have a condition called Panhypopituitarism, which means loss of all hormone secretion.

I have the following conditions as a direct result; hypothyroidism, adrenal deficiency, growth hormone deficiency, hypogonadism, diabetes insipidus (AVP - D) and Bitemporal Hemianopia (tunnel vision).

I take hormone replacement medication daily which includes Hydrocortisone, Eltroxin, Desmopressin, Growth Hormone and testosterone.

Last year I celebrated 30 years post surgery! As you can imagine I have tried every single GH drug on the market over the past 30 years.

I currently am taking 0.2mg of Growth Hormone daily in the form of Genotropin Miniquick.

It’s convenient as it’s simple to mix the power and liquid as they come in a single syringe an the unmixed drug can go unrefrigerated, which is convenient for travel.

For many years I searched online trying to find support groups. I was looking for support but also wanted to give back and support newly diagnosed patients.

In 2015 I became a volunteer co-ordinator with The Pituitary Foundation and in 2022 I became Director of The World Alliance of Pituitary Organizations (WAPO).

I now support patients diagnosed with conditions linked with the Pituitary Gland.

I also advocate for change and raise awareness and educate medical professionals to aid in early diagnosis.
Russell-Silver Syndrome and transitioning into adulthood

Russell-Silver Syndrome (RSS/SRS) has forced me to face many challenges throughout my life, both mentally and physically, but I believe that these challenges have encouraged a sense of resilience and ambition within myself. I am currently seventeen years old and thus beginning my transition into adulthood. Though the medical transition into adult care is a significant element within this period, I believe that other aspects such as employment, university application preparation, and beginning my A-Levels are just as, if not more, important for me as an individual.

I do not want Russell-Silver Syndrome to dominate my life, although I do not feel that I would have grown to be the same person without it. It is therefore important for me to focus on my life and education outside of RSS. You will discover that, as you read through this, my transition into adult care as someone with Russell-Silver Syndrome is far less significant of a concern in comparison to other segments of my life, such as my academics.

To be completely candid, having Russell-Silver Syndrome is not easy in the slightest. With it being a hidden disability, in a sense, I feel that my needs can often be overlooked by those who truly do not know me as a person, or who do not have an understanding of Russell-Silver. This presents additional challenges within itself. With my application for Personal Independence Payment (PIP), for instance, the person who took my initial assessment over the phone did not have an accurate understanding of RSS at all.

Having to undertake such an assessment was already difficult for me as it forced me to revisit past difficulties that are rather upsetting, however, in addition to the actual assessment, the assessor required me to provide them with an understanding of the condition at the beginning of the call, something I found quite difficult to do emotionally. In addition to this, due to my secondary school’s lack of understanding of Russell-Silver Syndrome, I did not receive the proper support during my exams that I would have needed. At my current Sixth Form, during exams I have extra time, rest breaks, and access to a computer to write my essays. At my secondary school, I only had rest breaks.

With RSS being quite a rare condition, I do not expect people that I meet to know all about it, in fact I prefer it when they don’t, so that I can keep my medical history private, hence why I am writing this blog anonymously. Therefore, it is understandable that I do not always receive the support that I need immediately. It is up to me to make others aware of what I do need, discreetly, so that I am not disadvantaged.

The mental and physical challenges that accompany RSS still have an impact on me every day. However, I have learnt to embrace this. I cannot simply ignore its existence; its existence has formed an integral part of me as a person, despite the challenges that it has led me to face over the past seventeen years. Having an understanding of RSS, and the impacts of it, highlights why I may find some activities difficult in comparison to my peers and allows me to find support for this so that I can achieve my potential.
I am a particularly ambitious person with regards to my own expectations of myself both in examinations and higher education. I feel that this began with my GCSEs. I worked incredibly hard in this period in order to achieve the best possible grades that I could.

The resilience that I had developed through my personal experiences and difficulties has translated to my self-motivation when it comes to studying and wanting to push myself during the more difficult periods. I have a clear understanding of what it is that I want to achieve and what is required to reach that. I genuinely believe that I would not be as determined to the extent that I am without my history with RSS.

Consequently, I was delighted to find that my hard work had paid off when I received my GCSE results in the Summer of 2022. I had achieved eight Grade 9’s and three Grade 8’s. Thus, going into Year 12 I had high expectations of myself. I have continued with my hard work, which hopefully will work in my favour and currently has, as I have achieved A*A*A in my end of Year 12 exams. My hope is that I will ultimately achieve A*A*A* in my A-Levels next year and go on to read law at a highly competitive university, such as the University of Cambridge. I believe that this is very much a possibility for me, and, I do not doubt that RSS has helped me to develop resilience and self-motivation that has allowed me to reach this stage.

It is clear that the disadvantages of Russell-Silver significantly outweigh the benefits, although, it is important to consider those few silver linings in order to live comfortably with Russell-Silver.

An important part of transitioning into adulthood, independently, is employment. From December 2022, I have been employed in a local supermarket. This experience has really highlighted to me the physical challenges, that I experience, that can be associated with RSS. Obviously, my short stature has an impact upon reaching places that are higher up, which affects putting items on the top shelf or reaching items for other customers. However, this has little actual impact due to the fact that there are a number of colleagues who are of a similar height, and even those of average height still struggle to reach higher up.

Consequently, all colleagues are provided with footstools. I am therefore no different to anyone else at work in this respect. Despite this, there are still several things that I do struggle with at work. Personally, I really struggle to stand for extended periods of time which makes my role particularly difficult as I can often be standing for eight hours at a time.

In addition to this, I have very small hands, about the size of a five year old's and my muscle mass is low which means that I often really struggle to open boxes to put items on the shelf. I work in a fast-paced environment which requires me to open stock, carry cases, and place them on the shelves rather quickly.

Due to my inability to open the boxes as quickly as others and carry them, I am not meeting the company’s targets which I did struggle with for a period as my work is constantly unfinished by the end of my shift and would often feel embarrassed by this. Although my employers do not know of my condition, they are aware that I am struggling with the pace purely due to my own physical ability as I am a focused individual and there really isn’t any other reason why I take as long as I do to work the stock. They are fairly accommodating of this and always plan for another colleague to pick up what I do not finish.
Arguably, the most significant issue that I have to deal with is the substantial number of comments from colleagues and customers about my size, although, I honestly don’t ever feel upset by them. It has reached a point where I simply have to laugh about it because there isn’t anything I can do. Comments would include ‘How old are you? Oh, I thought you were only 12.’, or ‘Sorry sweetheart didn’t see you there, you’re that small’, and my personal favourite, ‘When I saw you from down there, I thought you were 10. I thought your store was doing child labour!’ I usually just laugh it off, or twist it in a way that I can find entertainment within.

Being forced to serve and encounter so many different people has truly helped my confidence, resilience, and tolerance of comments about my size and appearance, something which I am very self-conscious of. I think it is essential that I showcase all aspects of life as teenager with Russell-Silver in order to provide an entirely realistic representation of the impact of the condition. I do not intend to worry parents or anyone with a diagnosis, but I do feel that it is absolutely crucial that I present a truthful account of my everyday experiences. Despite the issues that I face at work, I feel that choosing to undertake this job was the best possible thing for me, simply for the benefits that it has had for my confidence and the way in which I now present myself towards others.

During my secondary school experience, I really struggled with self-image which was exacerbated by the constant hurtful comments that I received from others in various year groups. This had a significant impact on my mental health during this period and has forever changed the way that I view myself. Working at this supermarket has not resolved this, but it has certainly led me to approach certain similar comments in a much more positive way and has given me the confidence to approach people both inside and outside work far more comfortably.

Ultimately, Russell-Silver Syndrome continues to affect my daily life, but I feel as though I am slowly beginning to learn to embrace its existence, and writing blogs such as this is the start of this journey. I have learnt to accept that Russell-Silver is who I am, but it is not all that I am. I, just like everyone with significant medical conditions, are so much more than a diagnosis. I understand that Russell-Silver will always impact my ability to complete certain activities in some way for the rest of my life, but it absolutely has not stopped me from pursuing my ambitions.
Our telephone support line is available to anyone concerned about their child’s growth or if they have a diagnosed growth condition. We are here to listen and support you. Call our nursing team on 020 8995 0257.

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

We have a range of closed Facebook groups enabling peer to peer support in the child growth community.

These groups provide a chat forum for parents and carers of children with a diagnosed growth condition and their families, for adults with the conditions themselves, and for those working towards a diagnosis.

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

We also have our main Child Growth Foundation Facebook group at www.facebook.com/groups/cgfoundation

After the launch of our ‘Top injection tips’ infographic, pictured right, we are extending our ‘For parents, by parents’ range.

For our next edition, we’d love to know: **What top tip or piece of information helped you when going to your GP when you were concerned about your child’s growth?**

Please share your suggestions with us at support@childgrowthfoundation.org.
Top injection tips from parents, for parents

- **Stay positive**
  - Keep yourself calm. Children can feed off your anxiety.
  - Be open and honest with your child. Show them you believe they can do it.

- **Speak in age appropriate language.**
  - You will have many conversations over the years with your child regarding the injections.

- **Consistency.** Make it part of their routine, just like brushing your teeth!

- **Try any distractions such as TV, ice packs, dummies or teddy bears.**
  - Don’t be afraid to use aids such as numbing cream.

- **Avoid making it the last thing you do before bed and have a nice activity afterwards like a story or cuddle.**

- **Try injection rotation, rotating between stomach, bum and thigh to find what feels best for your child, as some areas can hurt more than others.**

- **Name your injection pen.**
  - It makes it sound less medical and more friendly.

- **The first few weeks can be the worst.**
  - It’s okay for them to be upset.
I first heard of the Child Growth Foundation when looking through online groups after our son was diagnosed with Congenital Hypopituitarism at one week old.

I spent my days in hospital (while he was sleeping) trawling online forums and websites to try to learn and absorb all the information I could about his condition. CGF had a section on Hypopituitarism on their website which had lots of useful information.

My little boy had three hormones being replaced with medication before we left hospital so I knew this would more than likely include a growth hormone at some point too.

I felt incredibly isolated and lonely as a parent of a child with his condition. At the start everything was new and unknown so I was constantly reading and asking questions, then asking more questions about the answers to the first questions. The doctors and nurses hated to see me with my notebook!

Once everything settled and we got into our routine of medications, blood tests, sick day rules and crisis interventions I still felt that it would be lovely to have a face to face chat and a cup of tea with someone who had the same worries or challenges.

The online forums are fantastic but with so many people connected from all over the world there is sometimes conflicting advice and different countries dealing with things in different ways.

So, one day I posted a message on all the Facebook groups I had joined since my son was born. The team at CGF replied saying they would love to help facilitate a support group for parents and the idea has grown from there. I am excited to work with the CGF to create a support network for the small community of families in Northern Ireland living with Hypopituitarism.

I hope we can have a laugh, get to know each other and be able to support one another as and when we need it...and obviously a wee cup of tea/coffee too!
ARE YOU A PARENT OF A CHILD WITH HYPOPITUITARISM?

Join this new free parent support group

A group of parents are launching a friendly peer support group for parents and carers of children with Hypopituitarism in Northern Ireland.

To register your interest in joining this free group:

Email us at: support@childgrowthfoundation.org

Visit: childgrowthfoundation.org/mphd-parent-group-ni

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