



Autumn 2022 Newsletter

CALENDAR DATES

- Sun 25 Sept [Moving Up—Teen and young adult meet up](#)
Geek Retreat, Unit 1 Mulberry House, Park
Place Plaza, Stevenage SG1 1BF 1.00-3.00pm
- Sat 8 Oct [Family Support Meeting](#)
Hitchin Youth Trust, 111 Walsworth Rd,
Hitchin SG4 9SP 2.00-4.00pm
- Fri 21 Oct [New parent get together](#)
Inn on the Park Café, Verulamium Park, St
Albans AL3 4SW 10.00-12.00am
- Sat 12 Nov [Family Support Meeting](#)
Hitchin Youth Trust, 111 Walsworth Rd,
Hitchin SG4 9SP 2.00-4.00pm
- Sun 4 Dec [Up on Downs Christmas Party-Save the Date](#)
Venue TBC—3.00-5.00pm
- Fridays [Choices Youth Group](#)
Hitchin Youth Trust, 111 Walsworth Rd,
Hitchin SG4 9SP 6.15-8.00pm
- Mondays [Teen Fitness Group](#)
Via Zoom at 5.45pm
- Thursdays [Teen Social Communication Group](#)
Via Zoom at 6.30pm
- Saturdays [Speech Group Meetings](#)
Meeting Saturday mornings at various
locations



Up
On Downs

*If you have any questions
or
suggestions please
contact Sande, Jan or
Eleanor at:*

[enquiries.nhdowns
@yahoo.co.uk](mailto:enquiries.nhdowns@yahoo.co.uk)

*call:
(01727) 420365*

*Or visit:
www.upondowns.co.uk*





When Up on Downs Met the Geek Retreat



- by Eleanor

When I came across news that an inclusive community space was opening in Stevenage that had gaming at its heart I just knew I had to be there and saw that Up on Downs could benefit from such a venue.

I brought along my gaming partners (aka my children) to explore what the venue had to offer. The answer is a lot!



A wide variety of board games, card games, comics, computer games and books. If games are your thing then there will be something at the Geek Retreat to keep you amused.

The weekly programme is worth checking out with social mornings for home educators, knitting enthusiasts, lego clubs and learn to play sessions. There is something for everyone here. Look for the Geek Retreat on facebook and you will see for yourself just how much there is going on.

Even for the non-gaming adult there is also the café meaning coffee, milkshakes and other refreshments and a comfy chair space available to relax in.

Come and see for yourself as Up on Downs hosts a Teen event at the Geek Retreat this September.

"It's fun, fabulous
and the best"
A happy geek

Teen event @ Geek Retreat

25/09/22 1 - 3pm

Park Place Plaza,

Stevenage, SG1 1BF





Up on Downs Summer Fun

It might seem a little while ago now but we wanted to share some of the images from our summer outings. We had a lovely day on the canal with Waterways Experiences, it was one of the hottest days of the year but we had lots of hands on deck to help the crew.





Up on Downs Summer Fun

Later in July we had another great day at Standalone farm—thanks to all of those who came along and helped to make these days so enjoyable.



Up on Downs return to Magdalen Farm Wednesday 31st May—Friday 2nd June 2023

By popular demand we will be returning to Magdalen Farm and Environmental trust in the Summer half term of 2023.

Why not consider joining us to make some more special memories at this wonderful venue. In order to secure a place we will need to ask for deposits by the end of the year so please contact us at enquiries.nhdowns@yahoo.co.uk if your family are interested.





Youth Group for people with learning disabilities aged 12 – young adult

Join Choices for friendships and fun activities.
To relax, to create and to experience a positive atmosphere of inclusion.



WHEN: Friday evenings 6.15pm

WHERE: Hitchin Youth Trust, Walsworth Rd,
Hitchin, SG4 9SP

CONTACT: Magda - 07940 224165
magdapol75@hotmail.com

Supported by



Family Support Meetings

8th October and 12th November 2.00-4.00pm

Hitchin Youth Trust, 111 Walsworth Road SG4 9SP



We were really excited to see so many of you at our first Family meeting of the academic year in September, so lovely to catch up with all your news from the summer and meet new members too. It was the perfect opportunity to set the children to work on our image for the Up on Downs official Christmas card for 2022. We hope to have the cards professionally printed and ready for sale by our October meeting.



Join us in October where our crafts will take on an Autumnal theme and we will also have the regular fun, games, refreshments and some singing and signing. Most importantly, there will be the chance to chat together, Sande, Eleanor and Jan will be on hand to answer questions and signpost to sources of information and advice on all aspects of life with our special children.

Our Family meetings take place on the second Saturday of each month (except December when we need to make time for our Christmas party!) and are a drop in format so just come along if you are free. To let us know you'll be coming or if you have any questions please email us at: enquiries.nhdowns@yahoo.co.uk





New Parent Get Together

Friday 21st October—10.00am—12.00 midday

Inn on the Park Café, Verulamium Park, St Albans
AL3 4SW

We have been lucky to be joined by several new members over the summer so thought it would be a good time to get our parents of younger children together again to meet these gorgeous babies. If you are free this Friday morning and are one of our newer parents, or would like to meet them and share experiences do drop by to the Inn on the Park where Eleanor and Jan will be waiting, all children welcome. If the weather is favourable we can pop over to the nearby play area for any pre-schoolers with us.

Park at the nearby St Michaels Street car park (£1.95 for two hours, AL3 4SW), walk towards the main park and you will see the café. Contact us at enquiries.nhdowns@yahoo.co.uk or give Jan a ring on 07738470634 if you have any questions or would like to let us know you are coming.

New Down Syndrome Act 2022—Call for evidence

As many members will be aware the Down Syndrome Act received Royal Ascent in April of this year and the government are now consulting those with Down Syndrome and their parents and carers in a call for evidence. The information gathered in this consultation will help to form the statutory guidance that will be at the heart of the act. Here at Up on Downs we know all too well how hectic family life can be and keeping up with the administration for our young people could be a full time job itself but want to encourage all those who feel able to feed back into this important legislation.

You can submit your evidence using forms [here on the gov.uk website](#), these are also available in [easy read formats](#). The deadline for submitting them is 8th November 2022 but there are lots of [consultation events from the Downs's Syndrome Association](#) running currently and related information that you might want to take advantage of before you respond.



GOV.UK

[Call for Evidence](#)



GOV.UK

[Call for Evidence—easy read](#)



**DOWN'S
SYNDROME
ASSOCIATION**

[DSA—Information on the Call for Evidence](#)



*Save the date—Sunday 4th
December 3.00–5.00pm
Up on Downs Christmas Party
2022*

It may still be September but plans are already well underway for this year's Up on Downs Christmas party. Traditionally our biggest event of our calendar we are delighted to say we will be returning to full capacity this year so make sure you save this date in you diary as we'd love your family to be there with us.



Santa's Helpers Wanted

Up on Downs is seeking volunteer help to deliver a Christmas cracker of a party on December 4th.

Can you help to run the raffle?

Can you help find good quality prizes to help fundraise for the charity?

Do you have friends or family that can help with the refreshments or a stall?

Please email enquiries.nhdowns@yahoo.co.uk if you can help us in anyway. Your continuing support is always greatly appreciated

THANK YOU!



Anthea Bickerstaff, pictured here with son Joe, for raising a wonderful £270 for us with her birthday fundraiser. Thanks so much Anthea, hope you had a great birthday!



Sarah Stockley, for her continued support with her regular monthly donations—thanks so much!



If you would like to consider supporting our work with a one off or regular donation by visiting the [Up on Downs Charities Aid Foundation giving page](#).

ARE YOU A PARENT OF A 1-4 YEAR OLD CHILD WITH DOWN SYNDROME?

Opportunity for research participation

We are looking for parents of 1-4 year old children with Down syndrome to take part in a study about feeding and eating in early development.

You can take part in person (if local to Hertfordshire and the surrounding areas) or online.

The research involves weight and height measurements (if participating in person) and completing questionnaires about your child's feeding and eating twice, approximately 6-9 months apart. You also have the option to take part in a discussion with the researcher about your experiences and/or a video-recording of a mealtime if you would like to.

£15 gift voucher after taking part in each stage!

For more information, please contact Laura Hielscher at l.k.hielscher@herts.ac.uk or please feel free to contact Dr Silvana Mengoni on 01707 284494

Helping the Community

A number of exciting research projects are currently seeking participants with Down's Syndrome which will help inform and improve the future outlook for our community.

Laura Hielscher from the University of Hertfordshire is looking for parents of children aged 1-4 years for a feeding study. A previous study on the effect of the Covid lockdown on new mother's experiences on feeding services has already been published and is available to [review here](#).

If you fit the participant requirements please consider contacting UH to take part in this latest study.

Up on Downs has also been approached by a research group working in the University of Manchester School of Environment, Education and Development leading a study into language learning in children diagnosed with Down Syndrome.

The aim of the study is to learn more about whether retrieving words helps children to learn them. The study will take place on the video streaming platform Zoom in four sessions spread across two weeks.



The total duration of all these sessions will be no more than an hour (session 1 will take around 25 minutes, and sessions 2, 3, 4 will take around 10-15 minutes). We are looking for 8-12 year old children with Down syndrome, and 4-6 year old typically developing children to take part. We hope that our findings will help shape interventions and classrooms activities that will maximise their learning experience.

If you would like to learn more please email [enquiries.nhdowns@yahoo.co.uk](mailto:nhdowns@yahoo.co.uk) and we can forward the full participant information sheet and contact details to you.

HOW TO FIND UP ON DOWNS

You can find us in a variety of ways, whatever way suits you best please come and find us:



enquiries.nhdowns@yahoo.co.uk



Call us on (01727) 420365



Visit the website: www.upondowns.co.uk



Like Up on Downs on facebook



For members we have a private facebook group called Up on Downs Community. To request to join please go to our public page, click on groups tab to find the Up on Downs Community group.



Follow [upondowns_herts](#) on Instagram

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