



Up
On Downs

Autumn 2020 Newsletter

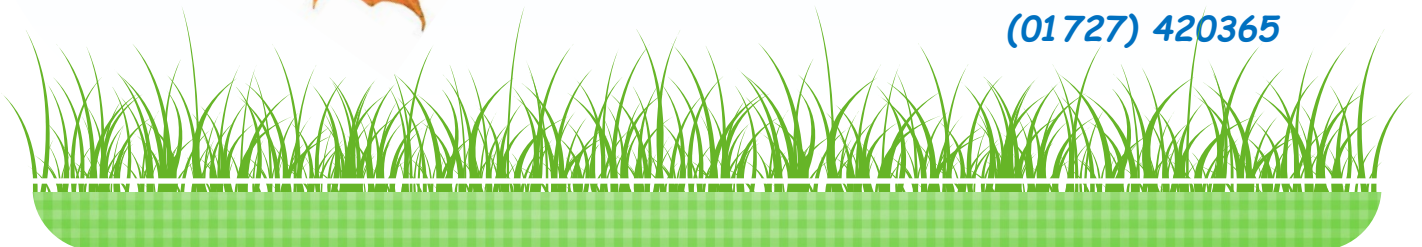


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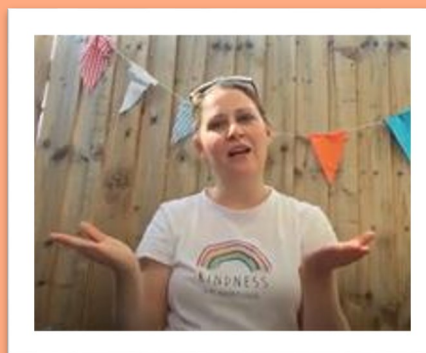


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Autumn Update

We hope you and your families are keeping well and that the start of the Autumn term has heralded the return to some sort of normality to your lives. However, with many schools already having to send some pupils home and the advent of the 'rule of six' this is normality with a very small n.



Eleanor in mid sign!



Signing along with Eleanor in full costume!

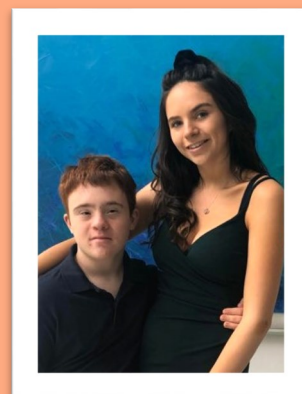
Here at Up on Downs we are really happy to have resumed our **Speech Group programme**, having fully risk assessed the meetings and bought in additional safety measures to ensure they comply with our Covid safe policy and our venue's regulations.

Other face to face gatherings, such as our regular **Family and Friends** meetings sadly can't take place in their usual format at the moment. In light of this we will be offering more 'virtual' events this term, the largest of which will be our **Zoom Halloween Party**, more details later in the newsletter.

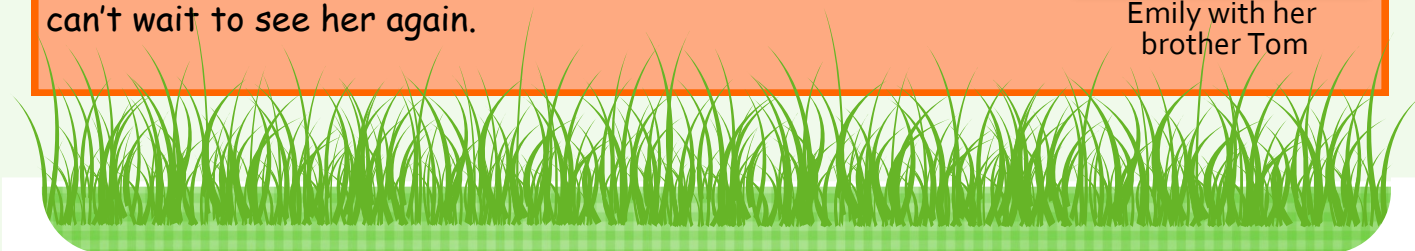


Eleanor will be hosting a new programme of her **Singing and Signing sessions** which were so well received over the summer. Her new sessions will be based around three classic stories; Dear Zoo, The Very Hungry Caterpillar and Kind and have lots of songs along the theme of the books to introduce useful signs.

Emily Enoch, the coordinator of our **Teen Zoom Group** over the Summer has now commenced her teacher training degree at university and we would like to think her for all the great fitness and conversation sessions and wish her all the very best with her studies. After half term Emily is going to be running more sessions for us and I know our teens and tweens can't wait to see her again.

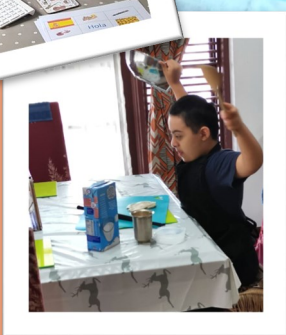
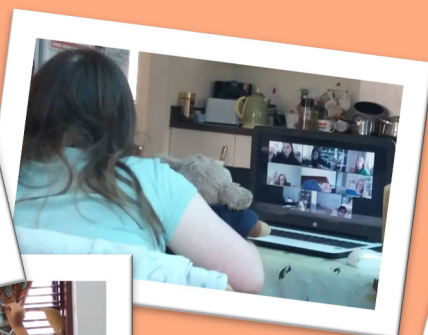


Emily with her brother Tom



Autumn Update continued

The first of our themed parent / carer **Zoom get togethers**, kicking off with the hot topic of managing challenging behaviour, will also take place this half term, do let us know if you would like to join the meeting.

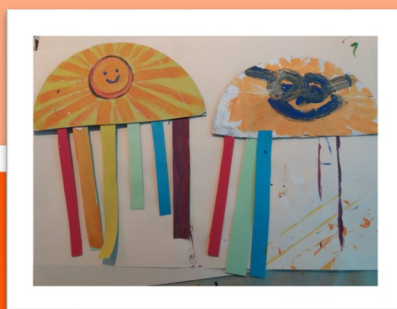


Some of our Zoomers working hard over the summer

We do hope to see many of you at some of these events so please join us for as much as your family would find useful. If there are any issues you would like advice about, an experience you would like to share or would just like a chat about something remember we are still here and would love the chance to be of any help we can, or just be a listening ear.....

Sande, Eleanor and Jan

Wednesday art club creations
From summer 2020





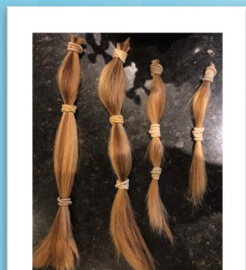
Emily Stockley

26th May 2010—2nd September 2019

The start of this month marked a year since we lost our dear friend Emily. Emily and her family, who are long term members and supporters of UoD were very much in our thoughts over this time.

Kirstie Lardner Fundraiser

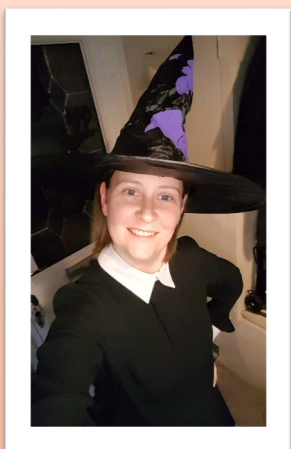
We were delighted to hear that friend of the family and one time nanny of Emily, Kirstie Lardner, was donating her lovely long hair to the Princess Trust and raising sponsorship for Up on Downs in Emily's memory on 8th September. Kirstie's super event has so far raised £490 and her fundraising page is still open [here](#) for those who would like to make a donation in Emily's memory. Thank you so much for your efforts on our behalf Kirstie, a beautiful way to remember our friend Emily and for sharing these lovely pictures of you and Emily together.



Diabetic ketoacidosis (DKA)

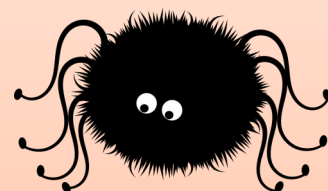
Since the incredibly sad loss of their daughter Sarah and Time Stockley have been working with medical experts to raise awareness of the serious condition DKA, Type 1 diabetes and their particular relevance to the Down's syndrome community. Please take a moment to read their enlightening and instructive account which we have circulated with this newsletter.





Halloween Party 2020

Via Zoom, Saturday 31st
October, 2.00-3.30pm

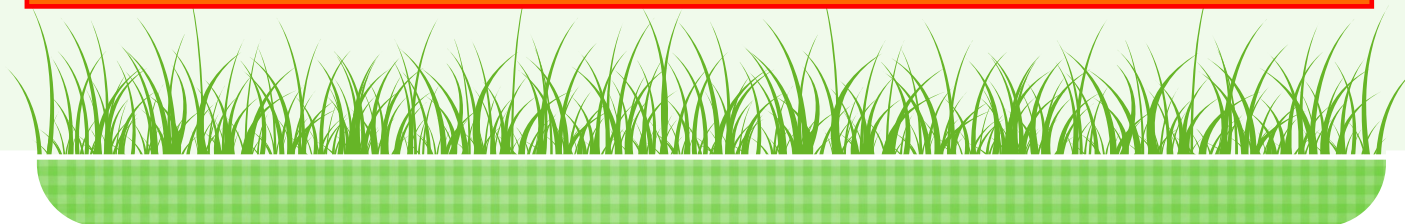


Be afraid (well, not that afraid!) the Up on Downs Halloween party is back, but in true 2020 style has gone online. Join us for 'virtually' the most fun you can have on a Saturday afternoon for our first Zoom Halloween party. There will be lots of music, fun and fancy dress, some spooky singing and signing, creepy crafts, ghoulish games and a signalong story from our very own Eleanor.

Full details will be provided in your invitation but there will be more treat than trick with prizes for all taking part; your little one can join in with as little or as much of the afternoon as they feel comfortable with. The event will be definitely more fun than fiendish!

If your family would like to take part just send an email to

enquiries.nhdowns@yahoo.co.uk—if you dare.....





Let's talk Makaton

Along with lockdown (sort of) easing there have also been a number of changes and exciting projects in the Makaton pipeline so, as the tag line suggests, 'Let's talk Makaton'

Makaton Hub

The Makaton website has recently undergone a lot of changes and is looking rather fabulous as the renovated '[Makaton Hub](#)'. As always there are free resources to make use of and currently a 20% discount on some resources as a Back 2 School offering.

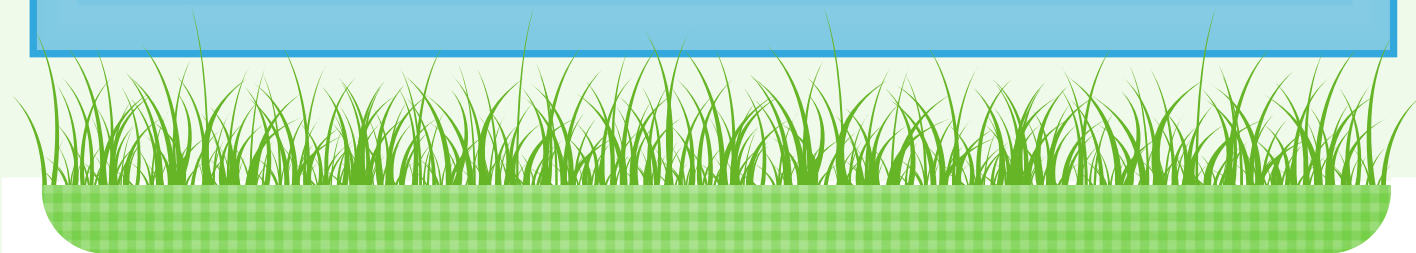
There is also a 'Core Membership' option available. There is a video on the website explaining the new membership and, even more excitingly, there is a 7-day free trial offer so you can examine the content before deciding whether or not you would want to invest. Please note you can still sign up for a free account as before.

Singing Hands

[Singing Hands](#) have been true lockdown heroes providing numerous examples of quality online content to keep us all on our Makaton toes and to entertain our children and young people. The content available on YouTube can keep you going for months (trust us on this!).

They will also be running another term of baby and pre-school signing classes via Zoom this term. Potentially useful for anyone who is still shielding or if your educational setting is still closed. If interested, please see their Facebook page or website for more information.

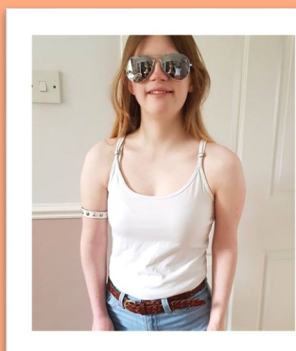
For parents and carers with an adventurous Makaton side you might also wish to check out the recently launched Singing Hands Choir concept or the 'Wine and Sign' events. Winter dates have been added to their website.



Independent Living—Lydia's Story

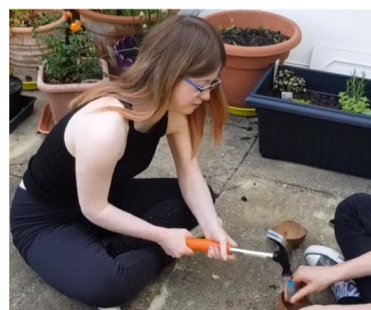
By Frances, Lydia's mother

From an early stage I've felt it important for Lydia to be as independent as possible. This is for a number of reasons, including her self-esteem, personal responsibility and growth, and not relying on her parents to look after her. How will she cope when I can't look after her?



In August 2019, when she was 19, Lydia moved into a transition supported living setting in Briar Patch in Letchworth (BP), where she had her own room and shared communal space with about 12 other young people, who had learning disabilities and a variety of care needs. She spent three days at North Herts College and two days having lessons at BP on self-help skills like budgeting and healthy eating, and there was a routine to include weekly shopping, washing and cleaning.

She settled very quickly, and wanted to make the most of the independence she had heard so much about. Unfortunately she began to realise that being independent meant she still had to get up early in order to be ready for the taxi taking her to college, and although she could choose what to eat, now she had to do her own washing up. But she thrived, and started to

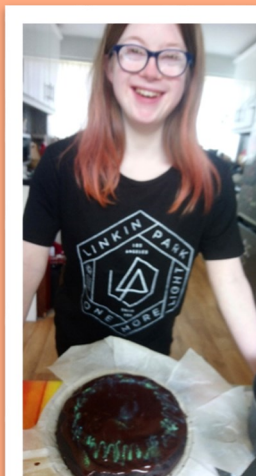


remember things like needing to pack her medication for an overnight stay, or being ready at a particular time for an activity - things she would have normally left to me.



In March 2020, as lockdown started, Lydia moved home. It was lovely to have her back, even more so once I had furlough leave which meant I could spend time supporting her with college activities, and her increasingly complicated baking requests. For the first time in many years we did art together, we dressed up and made silly videos, she willingly went for a walk every day, even if it meant pausing a favourite DVD part way through. It was a precious time.

Once the college work finished in June Lydia had more free time. I thought I could devise college type activities to keep her focussed, but somehow they never seemed as important when they were made up by Mum.



Independent Living—Lydia's Story continued

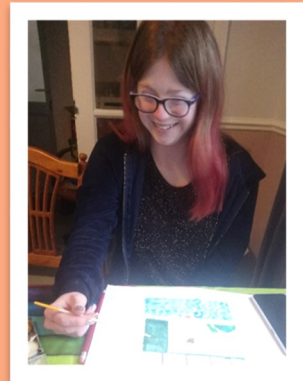


The screen time increased, the requests to make cakes reduced and help around the house returned to her pre-independent levels. I wondered if she was losing what she had gained in the months at Briar Patch.

In August an alternative supported living house was found, this time just a 10 minute walk away in Biggleswade, and having just turned 20, Lydia moved in. I was a bit unsure how things would go on her first day. She had been living with me for more than five months, and had a nice easy life. She knew that with independence comes responsibility and

chores. But as she unpacked her things she obviously didn't want me hanging around, and as I left she'd got her CD player going and was singing along to some new music. This is not a transition place, potentially she could live there forever. It is less structured than BP. We are putting together a timetable, based very much on what worked well from her previous routine, so she has a regular day for shopping, doing her washing, and the carers will implement it.

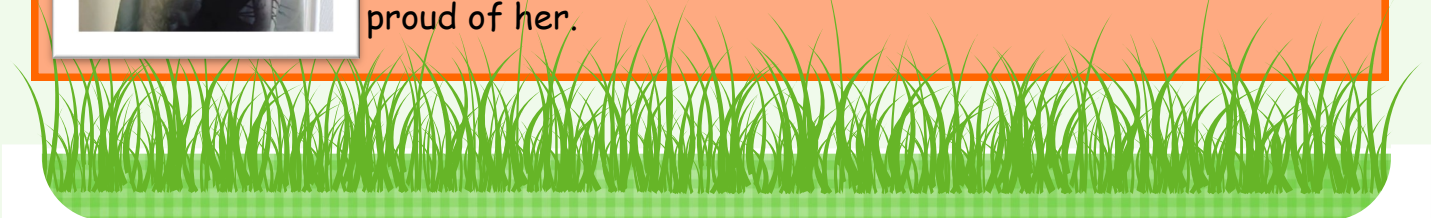
As with all new people and environments there is some getting used to each other. One weekend she planned to have food at the pub where her brother was working. I mentioned it to the staff so they would know to walk into town with her the next day. But come Sunday she told them she didn't want to go. What she meant was she didn't want to go with them! Once they realised she had gone out by herself, and after a few hurried phone calls they caught up with her in town as she was about to tuck into her lunch. The fact that she had walked there by herself and ordered her food is a credit to her abilities and confidence, it's just a bit more independence than what's currently



detailed on her support plan! Steps have been taken to stop her opening the front door unaided, and the carers will work with her to gradually increase where she can walk to by herself and when.



She pops round on a Friday evening to join in with our regular fish and chips, but then at 8:30 she looks at her watch and says it's time for her to go home. She doesn't want the easy option of staying with Mum, so now I have to go back to work full time, and watch from a little distance as she continues to develop as a young adult living in her own home. I am very proud of her.





Looking forward to Christmas

Is it too early to mention Christmas? Well it's good to have something to look forward to at the moment so we say 'No, it's not!'. Owing to the current situation we are still considering whether we will be holding our Christmas party in its traditional format or will have to think a bit more laterally. One thing is for certain, Santa will not forget any of our young, or young at heart, members and we will be celebrating. We'd love to hear your ideas.

Christmas Card Robins

The design for the 2020 Up on Downs Christmas card is going to once again feature the artwork of as many of our children as possible. We'd like children to colour, collage or decorate a festive robin in a Santa hat (template circulated with this newsletter). Send us a picture of their finished artwork and all the robins will be magic'd together onto a Christmas tree for the finished design! Some of our Wednesday Zoom art club members made an early start over the summer with these lovely collage robins. If you'd like us to send you a printed robin template or have any questions please just let us know. We can't wait to see your robins!



On Sale Now

At a time when keeping in touch with those we can't see in person is, perhaps, more important than ever we have stocks of these beautiful Christmas card designs by UoD members available now, for those who would like to get a head start on writing them. They are £5.00 for packs of ten (fingerprint penguin and Christmas tree designs) and £3.00 for packs of six (post box and merry Christmas handprint wreath designs). Email us to order yours.





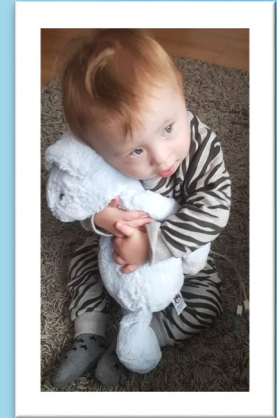
Fundraising News

In addition to Kirstie Lardner's efforts mentioned earlier in the newsletter we would like to say a huge thank you to others who have fundraised for or donated to us over the last few months. Not only do the funds help us to continue supporting families but these spontaneous acts of generosity have gladdened our hearts as we're sure they do yours.

Our warmest gratitude to: **Clare Carroll, Tracy Light, Clare McCawley, Erika Saunders and Rebecca Turner** for their generosity and kindness.

Blue Stevenson Raffle

Friend of the gorgeous Harlee Parker (pictured) and his family, Blue Stevenson, has been raising money by raffling items on Facebook, this generated donations of over £650. Amazing!

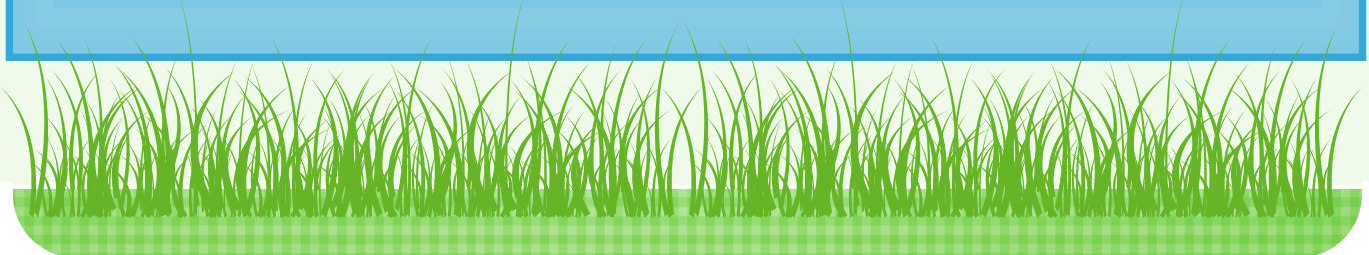


Abseiling Down the i360

Some brave staff at EV Cargo Logistics have raised over £550 by abseiling down the i360 in Brighton. This event, which was originally due to take place in March has instead proved a great finale to a year of fundraising events and our tenure as their Charity of the Year.

St Albans Abbey

We were delighted to, once again, have our work recognised by the congregation of St Albans Abbey and receive a grant of £1000 to use supporting families in the coming year. Only sorry not to see the Dean and representatives of other local charities at the cheque presentation, which couldn't take place this year.

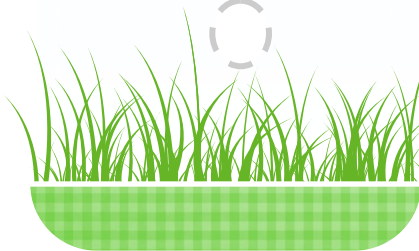




Up
On Downs

We have a closed Facebook group for members only: Up OnDowns (set up as an individual person on FaceBook.) To join this search for Up onDowns and you should see our balloon logo. Send us a friend request and if you're member we'll add you to the group. Look us up!

We also have a separate group Up on Downs has a FaceBook Group Up on Downs (note this one has a space between the on and Downs) which can be viewed by all that friends and family may wish to join, go to the page and 'like'.



Up on Downs, 20A Upper Culver Road, St. Albans, Herts, AL1 4EE

Registered Charity Number 1126111