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“What is Christmas? It is tenderness for the past,
courage for the present, hope for the future” *Agnes M Pahro*

***We wish you & your families Peace, Health & Happiness
this Yuletide & for all of 2021***

2020 what a year it has been



We continue to have so much to be truly grateful for during some extremely difficult times ...

Finola & Henri hope that the delivery of this newsletter and Christmas Health & Happiness wishes sees both you and all your loved ones in good health. It has been a year of extraordinary change/adjustments to us all and in some cases this has been life changing.

We truly hope that 2020 and Mother Nature has been kind to you and your families.



2020 HAS GIVEN US A YEAR OF GREAT OPPORTUNITY AS IT HAS GIVEN US TIME TO REFLECT & ADJUST & to be extremely grateful for what we have.

WHY GRATEFUL?

Well firstly we have to be grateful that Bruce Forbes came into our lives in 2018



This year we have been running with Henri as the only female carer since mid January (with the exception of Ashleigh see below) and Bruce. We have had to work very 'differently' and without Bruce there is no doubt this year would have been extremely difficult for both Finola and Henri. We were about to interview when lockdown happened and we decided in order to keep Finola and I, Bruce's family and Finola's next door neighbour, Alex, 'safe' we would continue with just ourselves.

It has not been easy but we have been extremely grateful that Gullane was so far advanced with overhead hoist/specialised

bed & mattress already in place. If it had not been prepared then we could not have been able to use Gullane for the lockdown.... and what a different experience that would have been. Finola normally has 5 friends helping her throughout the week. For transfers we would normally have 2 people assisting so 'blow me down' Orbit having watched is now volunteering himself as the 'other' person. Very well done Orbit what a star you are!



We are also very grateful to Bruce's sister in law, Ashleigh, who very kindly came to help whilst Bruce had a 2 week well deserved holiday in August. She stayed with us working 20 hrs per week for 3 months to help with the moves. Thank you so much Ashleigh!



THE FINOLA TRUST VAN



A BRAND NEW Renault Master Van was donated anonymously to The Finola Trust just before lockdown!

K & I Ltd received the van owing to the National lockdown in August. We are so very grateful to the donor as it means that instead of having to replace the van at £45,000 we are currently raising adaptation costs in the region of £20,000 (final figure unknown as at Dec 2020).

We have kept our only fundraising event for the year (Finola goes bald) justgiving link open until 31 January 2021 as we are having to utilise Finola Trust reserves to meet the expected costs, however more of an update regarding fundraising and where we are at, later in the newsletter.

WHAT IS HAPPENING WITH THE NEW VAN?

There have been complications owing to the new Renault Master model having a lower chassis. This has caused problems with getting the correct lowering suspension in order to allow Finola to enter the van safely. There have also been added problems with lockdowns/people on furlough & answers from Germany/Holland regarding the two available air suspension lowering kits, taking a time to be answered. However we are delighted to say that solutions are being found.. Having visited K&I

recently we can update you with some exciting images. Thank you very much to Scott and the team for their work to date. We are looking forward to January 2021!



& EVEN MORE REASONS TO BE GRATEFUL ... BOBATH SCOTLAND NOW NAMED CEREBRAL PALSY SCOTLAND



Finola and I would like to thank Philip Vervaeke, Finola's Clinical Specialist Physiotherapist for his wonderful work with Finola and to the Cerebral Palsy Scotland team as a whole for their continued support. The centre had to close during the National lockdown in March due to COVID-19 but reopened providing necessary and sorely missed 'hands on' treatment in July.

Finola received her first session 23rd July and has been fortunate to have had one session per month since. The centre is running on a vastly reduced capacity owing to the necessary health restrictions imposed to stop the spread of the virus ie one therapist working in the centre at any given time.

Despite Finola having had a considerable gap without physio therapy she is at a stage now where the majority of her session (after preparation) will see Finola working in 'free sitting' for a large proportion of the session.

In last years' newsletter I was indicating she was 'free sitting' up to 5 – 8 minutes. Now, on a good day, it can be anything up to 30 minutes plus - huge congratulations and very well done to you Finola!



WE MUST SAY A HUGE THANK YOU TO THE HELPING HANDS SCHEME (THE ROBERTSON TRUST) & THE BAYNE-JARDINE TRUST



Once again Finola and I would like to thank the Bayne-Jardine Trust who have very kindly supported Finola's visits to the Cerebral Palsy Centre this year. Owing to the pandemic Finola will only receive the 10 therapy sessions by the end of the financial year.

These sessions are vital to Finola's condition and we are truly grateful for your support and kindness. Thank you so much. We would also like to thank the Robertson Trust who via the Helping Hands Scheme sessions enables Finola to have the 10 therapy sessions at subsidised rates. We once again thank you most sincerely.

TO MAINTAIN LIFE WITHOUT PAIN.



Studies have shown that adults living with Cerebral Palsy up to 75% have to live with chronic pain. This can be from increased muscle tone, spasticity or dystonia forming a contributing factor. This type of pain often referred to as musculoskeletal pain can be localised in the back, shoulder, neck, foot/ankle, knee, hip and arm.

During lockdown Finola did indeed have a problem with her shoulder which is still ongoing at this time and so without Philip's knowledge and advice we could very easily be in a very different place – so once again thank you so much for helping us to keep Finola moving and hopefully not to have to live with pain.

TO AVOID FURTHER DEFORMITY OF THE SPINE. Finola has major scoliosis in her spine which currently affects the lower section. It is vital that we avoid further progression of deformity of the spine to protect her vital organs.

TO LEARN MECHANISMS ON HOW TO ASSIST HERSELF WHEN HER RIGHT ARM GOES INTO SPASM. Finola's right arm can go into spasm at sudden unexpected noises, if she is not feeling very well, overtired, if something or someone moves too quickly into her vision, if she is over exerting herself, if she is anxious.

TO MONITOR THE INCREASED TREMOR/SHAKE in her LEFT HAND & ARM. This started last year and has increased. We have had to largely use the manual wheelchair this year (Finola's own choice) owing to the left armrest being shaped as a gutter affect & so supports the arm. This has had a positive affect on reducing the tremors. The electric chair is currently awaiting the same adaptation and will be completed in December 2020.

MAINTAIN ALIGNMENT & COMFORT 24/7 through careful posture management, correct equipment & regular therapy

MAINTAIN THE ABILITY TO REMAIN WITHIN COMMUNITY SETTINGS & BE INDEPENDANT

Cerebral Palsy Scotland we truly thank you and especially Philip Vervaeke.

Cerebral Palsy Scotland mission is to help people with cerebral palsy build skills, knowledge, confidence and relationships. They advocate for the CP community to have life-long access to knowledgeable, compassionate services and support.

FINOLA RECEIVES A WONDERFUL MANUAL CHAIR



We yet again have to thank the Bayne-Jardine Trust for very kindly donating a really wonderful manual chair. Having been without a 'backup' chair for two years we were set to receive the chair on 31st March.

National lockdown put a stop to the delivery and we eventually received it on 14th August. Motus Medical who supplied the electric chair also supplied the manual and what a comfortable tilt in space manual chair it is.

Thank goodness it came as I have already indicated Finola has chosen to use it since it arrived as it has helped with her tremor in the right arm, which incidentally is her driving arm for the electric.

Thank you so much to the Bayne-Jardine Trust and thank you to Tom Dobson, Wheelchair & Seating Specialist from Motus Medical, for fitting Finola so well.

www.motusmedical.co.uk

medical
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WHAT DID WE ACHIEVE IN 2020?

Firstly we would like to thank Edinburgh City Council

WHY? Well not only have they continued supporting Finola's payments to Upward Mobility during the COVID-19 lockdown, despite the fact she was unable to attend; which resulted in the Edinburgh based charity being secured for the future and being able to offer face to face services when it was safe to do so (more of that later).

But they have also helped with

- Replacing the Clozitt Shower Chair which the Finola Trust originally bought in 2012, with an up to date version
- Ensured that our 24 hour funding for Finola for her personal assistants was backdated to last August
- Is currently assisting with replacing her reclining 'easy' chair which is now 20 years old
- And has agreed and recommended to Port of Leith Housing Association that Finola has a Chiltern Wispa 100 overhead hoist at Finola's home rather than the current hoist which is continually giving us problems

THANK YOU VERY MUCH.

I would like to especially thank Margaret Patterson & Callum Loughrie for all their support.

We would also like to recognise Catherine Montgomery from ILF Scotland for her support during lockdown and obviously for the funding that Finola receives from ILF Scotland for her personal assistants. THANK YOU so much.

Without the support from Edinburgh City Council and ILF Scotland Finola would not be able to live independently so huge thank you for enabling us to realise Finola's dreams.

"Being confident and believing in your own self-worth is necessary to achieving your potential"



WHAT ELSE HAVE WE ACHIEVED?

FINOLA'S BEDROOM PLUS BATHROOM IN EDINBURGH GET A MAKEOVER ALONG WITH ALL OF HER FAVOURITE POSTERS DURING LOCKDOWN!

During lockdown as we were all at Gullane, including Jasper the cat and of course Orbit, we took the opportunity to get Finola's bedroom and bathroom painted plus replace the carpet in Finola's bedroom.

What was the colour choice in Finola's bedroom? You have it Lipgloss PINK!

We have to say a massive thank you to John who very kindly agreed to do the painting for Finola on his own & what a great job he did. Thank you so very much you are a star!

We also framed all of Finola's precious posters during lockdown so here are some of the results..



WHAT ELSE HAPPENED?

GULLANE OUR SANCTUARY

As we were staying at Gullane during lockdown we were very lucky to experience the glorious weather in May and seeing the summer unfold. We had nature visiting sending pheasants, a hedgehog (of whom we still have), frogs and of course the birds... so so lucky. We took the opportunity of having picnics down at the end of the lane and ending the day with lighting the fire pit!

Here are some images to reflect how very lucky we were during the 8 months we made Gullane home for everyone.

"Home is where love resides, memories are created, friends always belong, and laughter never ends."



Sadly on the 2nd March 2020 we had to say goodbye to the beech tree and hedge to make way for the new footpath being built by Cala.



However after 7 months its wonderful to be able to say we now have a new beech hedge/ a replacement Silver Birch and a Jacob Rock Mountain Ash replacing the Beech Tree. This was not an easy road by any means but its done. Now to make sure it all grows!



WHAT ELSE HAS BEEN HAPPENING?



We have had a saga of leaks in the wet floor shower room owing to a previously badly fitted floor. Nothing could be

done during lockdown as 2 floors had to be lifted and a dehumidifier brought in! This has now all been rectified and the result is a brand new shower room plus a new foyer floor!

I would like to thank Jason Urquhart (Accessible Living Solutions - www.accessiblelivingsolutionsltd.com) and his team for the excellent service he provided and to Conrad from Edinburgh Carpet & Flooring Warehouse (www.edinburghcarpetwarehouse.co.uk) for his wonderful work as always. Thank you to you all.



LASTLY BUT NOT LEAST!

As we all had to move out for the renovations I took the opportunity of phoning John and I am delighted to say he agreed along with his colleague Garry to come & paint Gullane. I have to thank most sincerely Garry and John who very kindly travelled for a week to paint every single room! They also renovating the kitchen cupboards – thank you so much! I am truly grateful to you both and so very proud of Gullane!

THANK YOU!

UPWARD MOBILITY UPDATE & HOW IS FINOLA'S BOOK PROGRESSING?



Well sadly having reported that the story was finished in last years' newsletter technology & human actions mislaid the final version.

However we are delighted that this is being resolved as Charlotte from Upward Mobility has been coming to Finola's flat each week since mid November to regain that which has been lost... and dare I say more!

The prime purpose of the weekly visit is to finalise the story as nearly four months worth of work has been misplaced. We are very grateful to Charlotte and to Upward Mobility for rectifying the situation and we are looking forward very much to the finished article. Once completed we will be meeting with Chris Hernandez (the illustrator).



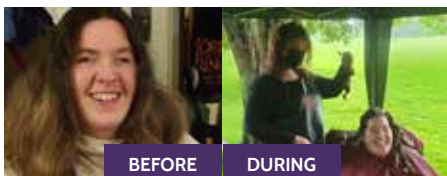
I am not going to say when it will be published but just that it definitely will be and should anyone wish to note their interest please let me know by emailing henri@finolatrust.co.uk

FUNDRAISING - WHAT'S BEEN HAPPENING?

Well as we are all very aware this year is not a time when you feel comfortable about asking people for help. It has brought too many great hardships and worries for the future. However I have to thank family and friends for their great kindness as we have experienced some very kind donations towards adapting the new van. It doesn't matter how big or how small as every penny adds up.

All our fundraising ideas had to be put on hold owing to COVID-19, except for one – **FINOLA SHAVES ALL HER HAIR OFF FOR THE LITTLE PRINCESS TRUST** !
<https://www.justgiving.com/crowdfunding/finolagoesbald4littleprincesstrust>

Finola came up with this idea herself and wanting to help others less fortunate than herself and at the same time do something towards raising funds for the van. On a very damp and 'dreich' day (in fact the worst day of the summer!) a trepid band assembled at Pilrig Park on 17th August to watch Finola have her hair shaved all off for the Little Princess Trust (<https://www.littleprincesses.org.uk>) a Charity that makes wigs for cancer patients, children and young adults. She donated 13 bunches of her own hair. Very well done to a courageous and thoughtful young woman. I as your mother am extremely proud of you. Well done Finola!



Thank you from Little princess trust

We would like to say a massive thank you to

Sharon the hairdresser, @sharonthehairdresser, who very kindly gave her time to shave off all of Finola's beautiful hair and to

Andrew Crow, www.eventvideoservices.co.uk, who kindly supplied the PA and filmed the event for us also on his own time

Thank you so very much to you both for your help and support.

You can watch more here: www.mediafire.com/file/7igmkz6wr1k3m79/file



It just happened to be Bruce's special birthday so we HAD to mark that too!

**FUNDS RAISED BY FINOLA'S
HEADSHAVE ON 17 AUGUST 2020
ONLINE - £3595**

(as at 11.12.20 – funds will be received early February 2021 less Justgiving fees which are currently unknown)

OFFLINE - £2,987

GRAND TOTAL = £6,582

Thank you so much to everyone who came to support Finola on such a dreary day & a huge thank you once more to Sharon & Andrew. You are both stars!

**TOTAL FUNDS AVAILABLE TOWARDS THE VAN
ADAPTATIONS as at 11.12.20 without using the
Finola Trust reserves
= £11,600 (funds previously raised)**

PLUS FINOLA'S HEADSHAVE TOTAL = £6,582

**TOTAL VAN ADAPTATIONS BUDGET AVAILABLE
= £18,182**

Currently we will need to utilise £1,818 of Finola Trust Reserves

however should you wish to help us to retain some 'reserves' for the 'unexpected' future, then we have kept the link 'live' until 31st January 2021

please visit:

(<https://www.justgiving.com/crowdfunding/finolagoesbald4littleprincesstrust>)

HUGE THANK YOU to everyone who has supported Finola in this extremely difficult year and to all those previously. We are truly grateful to you all.

To list everyone's kind donation would take a few pages so we would especially like to thank the following:

Grandad and Callum (dad), Jacqui, Nicky, Andrew, the Griggs family, Scott and Meriel, Gary and Heather, Gail and Graham, Claire and Rob, Michelle and Charles, Elisabeth & Rupert, Ashleigh and Andrew, Kathleen, residents from 23 Jameson Place, Mary and the residents of Gullane and to absolutely everyone who supported Finola in raising the massive £6,582 and of course the

biggest thank you EVER to the anonymous donor of the new van. **THANK YOU TO YOU ALL.**



WITH GRATEFUL THANKS TO MARY MIDDLEMISS

We have to say a very special thank you to Mary Middlemiss whom unbeknown to us having seen the poster on the van took it upon herself to walk around Gullane asking for donations on behalf of Finola's cause. A massive £432 was raised. Thank you so very much Mary and to everyone who contributed. Hopefully in January you will get to see where your contributions have gone. Thank you so very much for your kindness.

We have yet more THANK YOUs to say as we were presented recently with the most gorgeous cushion handmade by Mrs Doreen Tarbit. We raised a further £300 through family donations rather than auctioning it, so the cushion now sits



proudly on Finola's sofa. Thank you so much Mrs Tarbit for your very kind gift and hard work, and thank you to the family!

OUR GOODBYES DURING 2020

Sadly we had to say goodbye to wonderful Bree, mother/grandmas whippet. She had to be put to sleep exactly 2 years to the day since mother's passing. Thank you so much Rosemary & Bruno for giving her 2 wonderfully happy years and looking after her so well. We miss you still 'wee Bree'.



GOOD BYE AND THANK YOU

This year we have largely run with just 2 friends/personal assistants – myself and Bruce. However KERRI CARLIN stayed with us until 20 January 2020 which we thank you very much for. You later in the year became a mummy yourself – congratulations Kerri & Peter on your son Cairo!





ASHLEIGH FORBES again we say thank you very much for coming to us from end August – November. We are extremely grateful for your time with us. I hope that we will see you at some point next year.

Our Summer at Gullane



OUR GRATEFUL THANKS GO TO:

ABBAYHILL FOOTCARE HCPC REG. PODIATRISTS



ABBAYHILL FOOTCARE CLINIC

www.abbeyhillfootcare.co.uk



On 28th February Ruairi and Aideen from Abbeyhill Footcare clinic kindly came and performed surgery within Finola's own home. It went extremely well and we are delighted that this happened prior to lockdown as Finola was in quite a bit of discomfort. Finola as it was had been having to wear dressings for a year so thank you Ruairi and Aideen for your expertise and flexibility.



K & I LTD COACH BUILDERS

Hardengreen, Eskbank

We would like to thank Scott and the team for looking after our faithful friend (the current van) so well through this year and previous. It will be sad to see it go however we have to say we are really excited about receiving the new van in January 2021! Thank you so much for everything.

**LOTHIAN CENTRE FOR
INTEGRATED LIVING**

www.lothiancil.org.uk



Finola and I would like to say a very big thank you as always to this wonderful organisation that processes wages and also supports with advertising for new life enabling companions/friends. Obviously we have not been able to utilise this part of your service during this crazy year however we hope to utilise your service during spring of next year!

UPMO

www.upmo.org



We would like to say despite having only been able to attend Jan – March this year we are really pleased that Charlotte could come to Finola from mid November in order that her book can be completed. Thank you Charlotte & UPMO!



MOTUS MEDICAL LTD

www.motusmedical.co.uk

We would like to thank Tom Dobson and the team for being such a wonderful service. We are extremely grateful for all your help and look forward to getting Finola back into the electric wheelchair during December.



www.winkcreative.co.uk

Last but by no means least we would like to thank Will for all your help with the Finola Trust website and for this years newsletter. We are extremely grateful for your support and kindness.



WE WISH YOU AND YOUR FAMILIES A SAFE, HAPPY & HEALTHY CHRISTMAS
& NEW YEAR. MAY 2021 BE KIND TO US ALL.

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the **finola**
trust

Maximising the Ability
Minimising the Disability