



# Link

NEWSLETTER SUMMER 2020

**Editor's Note**

Hi all! What a strange time we are in at the moment! I hope all our members are getting through and staying safe at this difficult time for all of us. This short 'lockdown' edition of the newsletter will hopefully inspire you to share your stories and experiences with us so that we can all feel supported by each other in the WDS 'family'!

It has been unfortunate that we have been unable to have our Family Day meet up this year but I hope that we will be able to meet up with our members again soon. Take care.

Nicki Turley



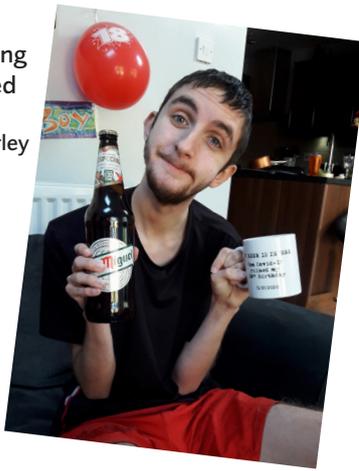
**HAPPY 18th!**

Callum has now finished school, of course much earlier than planned, but he is looking forward to starting college in September.

Despite celebrating his 18th birthday in 'lockdown', he received lots of lovely messages, cards and gifts (mostly beer) and participated in video chats. He has said, "It has been an amazing birthday that I will never forget!"

He has also been busy home learning and has had a lot of time to get used to his new house!

Nicki Turley



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Don't forget to send your articles or any news that you would like to see in future issues to: [secretary@wdssg.org.uk](mailto:secretary@wdssg.org.uk)

Please let me know if you have anything that you would like to share with other members.



# Lives in lockdown...

## From the Chair

Welcome all, what a strange year this is turning out to be? As the saying goes, I do hope you are all keeping safe, Many of you, like myself, will be in isolation due to the risks associated with WDS and chest infections etc. There is a fine balance over protecting yourselves and loved ones and the mental impact being safe at home is having on everything.

This is one of the reasons why I am asking what have you been up to while on Lockdown? I know some of you have been building Lego where others have been learning a new skill and some of you have been catching up on Netflix and Disney Plus. We are putting together a series of online resources allowing you to share your stories so please do send them in to me, We have had an increase of parents asking for advice and would love to share what you have been doing. I have been keeping busy at home 3D printing face masks for the NHS. I also took part in the 2.6 challenge by driving 26 laps of the 26km circuit of the Nurburgring in the game Forza Motorsport to raise funds for work which is currently closed. It took me over 4 hours to do but really enjoyed it and did something I never thought I would be happy doing which is streaming it live on twitch.

I also wanted to keep you all informed on what I have been doing to better enable you all to get the support you need. Some of you may have seen I did some question and answer sessions on Facebook, do take a look if you haven't watched them. I have had good feedback from people. I have wanted to expand on this a little and with the family day being cancelled we could hold a ZOOM like meeting service. I am keen to try this out before our AGM is due so if you are up for it for me maybe we could arrange for a group of us to join in? Many of you know I like my technology and because of privacy I have set up our very own online meeting service for members only. This can be found at [meet.wdssg.org/members](https://meet.wdssg.org/members) at present the service is only active once one of the committee members has set up a meeting. With everything done online now I have wanted a place for everyone to come and feel safe to chat. More details about this to come so please subscribe to our newsletters and Facebook pages. If we don't have your email please make sure it is up to date, we will only send out emails when something important to say and will never spam your mailbox or give your email out to anyone without asking you first.

Kind Regards  
Mark Mayer



Hi, during lockdown I have spent some time in the garage building a model Eindecker EIII (E3) a first world war German fighter that rules the skies of the western front for a short period in 1915-16. Otherwise I have been digging the allotment and growing seed in the greenhouse with Vanessa.

John Butt



Martin has a trough from Growing Places. He planted it with tomatoes and is looking after them in our poly tunnel. He is also organising a sunflower growing competition.

Affiliated to Contact a Family and Rare Diseases UK

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