

CLYDE AGAINST CHORDOMA

OFFICIAL EVENT GUIDE



SEPTEMBER 2021





About us...

Wally Van Laarhoven, David Andrewartha & Clyde the dragon!

I'm Wally. I am a mother, wife, colleague, nurse, friend AND... runner!

In October 2020 I was suddenly a PATIENT. And everything else faded into the background. A fierce period in which it turned out that I have a Chordoma in my head.

A 1 in a million chance! A rare cancer about which little is known and for which there is STILL no cure.

I have already had 2 operations and now we have to wait and see how the future will go. I continue my life as best as I can.

During my recovery I found a lot of support from the information and the fellow sufferers from the 'Chordoma Foundation'. I would like to give something back and what better than through my favorite activity: running!

Running helps me a lot in my rehabilitation process. Both physically and mentally.

I met Dave in Cornwall, England on holiday in 2019. He organised a marathon in the town near our campsite. A great marathon in a very beautiful area. It was 'The Island Marathon'. 64 times around an outcrop on St Ives Bay in Cornwall.

Dave is a runner but also has a small event company called 'Bys Vyken Events', with which he organises all kinds of activities related to running. He regularly organises charity runs. His underlying reason is that he wants to make a difference to people's lives through doing what he loves.

During the lockdowns Dave also organised several virtual runs. And now he would like to organise this event 'Clyde Against Chordoma'. Clyde is the mascot of Dave and 'Bys Vyken Events'. So it's an honor that Clyde is participating!

Clyde is a cuddly dragon who mainly loves cabbage, ice cream and gravy. He has his own Facebook page called 'Clydey TV', where he regularly sings along to his favourite music either on his own or with Dave, and he has segments called 'Tidey Clydey' where he tells us what the tide is doing, and he often can be seen annoying Dave's wife, Sally.

Clyde has been a part of other virtual running adventures, like 'I Dino What I'd Do Without You' with best friend Timmy the T-Rex, and 'Clydemare On Elm Street', which was a virtual Halloween run.











Wally, Dave, Timmy & Clyde @ The Island Marathon, St Ives, Cornwall (2019)



The Chordoma Foundation is a non-profit organisation working to improve the lives of those affected by chordoma and leading the search for a cure.

We envision a future in which everyone affected by chordoma are able to overcome the disease and maintain their quality of life.

Over the past decade, we've created a global movement of patients, families, doctors, and researchers working together to improve the odds for everyone affected by this disease. During that time:

- Chordoma research has advanced dramatically: from knowing virtually nothing about the disease to 7 promising drugs entering clinical trials.
- We have built a network of more than 400 chordoma specialists across the world, including nearly every leading chordoma treatment team in the U.S. and Europe, and produced clinical guidelines for diagnosing and treating chordoma.
- The Foundation has become a trusted resource for thousands of chordoma patients and their caregivers across the world, with a growing suite of services designed to meet the unique needs of the chordoma community.

But what gives us the most hope is that the ground we've gained thus far has made it possible for patients to begin benefitting from advances in research in a matter of years rather than decades.

What is Chordoma?

Chordoma is a slow growing cancer of tissue found inside the spine. Chordoma can happen anywhere along the spine. It is most often found near the tailbone (called a sacral tumour) or where the spine meets the skull (called a clival tumour). Chordoma is also called 'notochordal sarcoma'.

Chordomas form from the left-over cells that were important in the development of the spine before birth. These cells are called notochord cells. When the notochord cells don't disappear after birth, they can turn into chordomas.

Chordomas grow very slowly. Many people don't notice any change in their bodies for years. When they do start to have symptoms, it can take a while for the chordoma to be discovered and diagnosed.

Most people are diagnosed with chordoma in their 50s and 60s. Pediatric chordomas make up 5% of all chordoma diagnoses. Females are diagnosed slightly more often than males in childhood. Males are more often diagnosed as adults.

How common is chordoma?

Worldwide, one in one million people are diagnosed with chordoma per year!

How is chordoma diagnosed?

Symptoms of chordoma can be very different depending on where in your spine the chordoma starts. When chordoma starts at the base of the skull you may have headaches or double vision. Chordoma near the tailbone can cause pain down your legs and trouble controlling your bladder or bowels.

How is chordoma treated?

When possible, chordomas are removed with surgery. Radiation therapy is sometimes used after surgery, or alone if surgery is not possible. Chordomas can be difficult to treat because they grow on the spine, near important tissues like nerves and blood vessels. It can be hard to get all of the tumour out of your spine without hurting the healthy parts of your body.

New research is being done using immunotherapy to treat chordomas and to find other treatments. Immunotherapy is a cancer treatment that uses the body's immune system to fight the disease.



YOU CHOOSE THE DISTANCE AND THE ACTIVITY TYPE. AS LONG AS YOUR CHALLENGE IS COMPLETED USING ONE ACTIVITY.

YOU CAN RUN, WALK, CYCLE, SWIM OR EVEN DONATE IF YOU DON'T WANT TO GET INVOLVED WITH ONE OF THE FOUR LISTED ACTIVITIES.

- YOUR DISTANCE
 - YOUR PACE
 - YOUR ROUTE

YOU WILL HAVE THE WHOLE MONTH OF SEPTEMBER TO COMPLETE YOUR CHALLENGE TO RECEIVE A LIMITED 'CLYDE AGAINST CHORDOMA' BESPOKE MEDAL. ALL YOU HAVE TO DO IS LOG YOUR DATA USING A SCREENSHOT OR STRAVA/GARMIN INFORMATION ON THE RUN TO THE WEB PAGE THAT WILL BE SENT IN THE DAYS BEFORE THE EVENT.

THERE WILL BE A LEADER BOARD FOR ALL THE DIFFERENT ACTIVITIES, SO THERE WILL BE 4 ALL TOGETHER MEANING THERE WILL BE ONE FOR EACH.

THERE WILL BE A TROPHY FOR THE TOP NAME ON EACH ACTIVITY BY THE END OF SEPTEMBER.

ANYONE WHO DECIDES TO DONATE TO THE CAUSE INSTEAD OF TAKING PART IN ANY ACTIVITY WILL RECEIVE A BESPOKE SNOOD TO SAY THANK YOU. THIS WILL BE ON DONATIONS OF £10GBP OR MORE ONLY.

YOU CAN DONATE AT:

HTTPS://WWW.IMPACT.CHORDOMAFOUNDATION.ORG/FUNDRAISER/3347329

JUST A SCREENSHOT OF AN EMAIL CONFIRMATION WILL DO. DONATIONS CAN BE MADE ON THE EVENT PAGE CLICKING THE 'DONATE HERE' BUTTON OR AT:

CHORDOMAFOUNDATION.ORG

LOOK FURTHER INTO THE GUIDE FOR THE COMPLETE TERMS AND CONDITIONS OF THE CHALLENGE.

ANY QUESTIONS ABOUT THE CHALLENGE AFTER YOU'VE READ ALL OF THE INFORMATION THEN PLEASE EMAIL US AT:

BYSVYKENCORNISHTRAILS@GMAIL.COM

Clydey...















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TERMS & CONDITIONS

Your challenge must be completed at any time between 1/9/21 and 30/9/21. There is no minimum distance to this challenge. If you want to do 1 mile or 100 miles or anything in between or more, it's all accepted. You are in charge of your own adventure and own destiny. You can run, walk, cycle or swim. This challenge is just about getting you outside and achieving whilst raising money for this one in a million cancer charity. If you don't want to take part in the exercising then you can still donate. Details of donations and how to donate are online and within this guide. Any donation of £10GBP or higher qualifies you for a bespoke snood/buffalike/wrag/multifunctional headwear. The donation page has been put together by Wally Van Laarhoven, who is a friend, chordoma sufferer and event partner on this challenge. Please only make a donation on the donation page. Do not try to enter on the donation page. You must enter on the RiderHQ entry system if you want to take part in an activity. We need your details to process your entry. We can't do this from the donation page. You can do the challenge by running an organised running event/race if you wish or a social or training run/challenge for yourself. If you are partaking in another virtual challenge from us or another company/running organisation, you can include these miles for that challenge also.

All participants will receive a link for a separate webpage (differs to the one you entered with) so you can upload your data to the respective leader boards of the challenges. You can use screenshots of your data and/or upload the links to your activity from Strava/Garmin/Run Keeper or the like. You'll get a prize/trophy for 1st place on all challenges *ONLY*. The Run, walk, cycle or swim leader boards will be kept separate to maintain fairness and the integrity of the event. There will be no swapping of what challenge you'd like to do, so if you choose to swim you'll have to swim and you won't be able to exchange over to a walk. Only data and/or photo to will be accepted as qualification for a bespoke 'Clyde' medal and signed 'Clyde' art card. *Any* data sent and posted via Instagram, Facebook, Twitter or email will *not* be counted. These have to be logged by you on the link sent by our tech support guru, Adrian.

Please send photos including that of you wearing your printed bib (you're responsible for bib printing and ink and energy costs) on our Facebook pages however. There is a group page set up and a link to that page should have been made available to you upon receiving your bespoke bib number. Please note that even though this isn't an actual race, you are advised to still write emergency information and your name on the back of your bespoke number in case of an emergency.

You are advised to keep away from built up areas and are advised to maintain 2 metres (6ft) of distance between yourself and anyone else. Even though some restrictions may have been lifted for some, it's currently for the best due to the ongoing pandemic and severe U-turning from the UK

government. WE ARE NOT RESPONSIBLE FOR YOUR GENERAL HEALTH WHEN YOU ARE A PART OF THIS CHALLENGE. BE SMART AND BE SENSIBLE AND IF YOU ARE SICK AND/OR SHOWING SIGNS OF COVID – 19 THEN PLEASE DO NOT RUN. WE ENCOURAGE TESTING AND THE RECORDING OF YOUR TEST RESULTS PRE AND POST-RUN.

YOU ARE ADVISED TO SEEK WHAT YOU CAN AND CANNOT DO IN TERMS OF RESTRICTIONS WHEREVER YOU ARE IN THE WORLD.

This is not an actual race. This is a personal challenge. You will be responsible for picking your own routes/paths/journey and the number of miles you decide to take on. You can use treadmills on this challenge if you want to, particularly if you feel that being at home is something you must do because you either need to shield or self-isolate.

You are advised to keep to **ALL** public rights of way only and are advised to respect the basic environmental codes of closing **ALL** gates and not littering anywhere on your chosen route and respecting all landowners and their livestock, if any.

You are strongly advised to not wild swim and if you ignore the advice you should swim only if you are equipped to do so. Please respect the water and always check the tides before heading out on any outing.

You are advised not to run on main busy roads or lay out signage for your own challenge. If you do (because you think it will add fun to your challenge) then please <u>**DO NOT**</u> put any writing or moniker on the signage that suggests it's anything to do with Bys Vyken Events & Cornish Trails or The Chordoma Foundation, as we do not condone the littering of anywhere on any route(s) you choose and do not want to be associated with said littering.

Upon signing up for this challenge and adventure, you are agreeing to all these rules and regulations laid out in these terms and conditions and declare yourself fit and capable of running ,walking , cycling or swimming the distance you've decided to do.

Even though there will be leader boards on the challenge, not everybody will be running, walking, cycling or swimming the same routes and same places/distances. By completing what you set out to do means you've won regardless anyway, no matter what. You will all achieve something great come the end of this challenge, and it's all about this great charity and the one in a million cancer type that it continues to help fight against.

Bys Vyken Events & Cornish Trails and their race directors, David Andrewartha & Sally Galsworthy, Bys Vyken Race Team, every landowner, tenant or charity responsible for maintaining the area(s) in which you decide to run are not responsible for the route you take, the gear that you wear whilst doing so, the nutrition and hydration, or lack of that you take with you or indeed your injury, health or death whilst pursuing this challenge. The Chordoma Foundation are not responsible for the organisation of this event. They are merely the charity in which we are raising money for. We will have no marshals or aid stations or maps on your route. This is <u>YOUR</u> route remember. We have no say over where you go or how fast you do it in. You assume complete responsibility of yourselves and your own environment. Sticking to public rights of way and taking and reading a map is advised and essential in all places. It's recommended that you figure out where you're going before leaving your home. You are responsible for yourself and recommend that challengers under the age of 16 should be accompanied by an adult.

You are ultimately responsible for sticking to the Government guidelines surrounding what we can and cannot do during the Covid-19 pandemic/crisis.

You are advised to read the do's and don'ts on the Gov.uk/coronavirus site (if in the UK. Please check your own Government site wherever you are in the world if anywhere outside of the UK). By reading this and entering, you are accepting liability.

ALL PHOTOS/IMAGES THAT ARE POSTED BY YOU ON OUR SOCIAL MEDIA AND/OR EMAILED TO US WILL MEAN YOU GIVE US PERMISSION TO USE THEM FOR PUBLICATION AND PROMOTION OF THIS AND FUTURE EVENTS. YOUR IMAGES MAY BE USED TO ADD TO CERTAIN FACEBOOK ALBUMS BUT WILL NEVER BE SHARED TO ANY OTHER PAGE THAT'S NOT OWNED BY BYS VYKEN EVENTS & CORNISH TRAILS OR WITH ANY INDIVIDUAL. BY SENDING TO US, POSTING ON OUR PAGES OR TAGGING IN SOCIAL MEDIA POSTS, YOU GIVE US PERMISSION TO USE YOUR IMAGES/LIKENESS'.

There will be a no refund policy in place and you will not be allowed to transfer or defer to an actual event held by us or any other virtual challenge held by us or anyone else. IN THE EVENT OF AN EMERGENCY DIAL 999 (IN THE UK. PLEASE CHECK EMERGENCY SERVICES NUMBER IF YOUR'RE OUTSIDE OF THE UK) where you will be able to contact ambulance, police, fire and coastguard services. Please respect the environmental code. Close all gates behind you and do not litter the area where you run/walk (as previously stated within these terms).

Downloading 'what3words' may help with your positioning if you get lost and need assistance from emergency services.

You must understand that your event fee will be used for the administration of your entry and your medal and posting of said medal before any money for charity or profit is declared.

We are not responsible for the supply of any PPE in your challenge. Be sensible and stay safe and remain and stay alert and be respectful to others on your challenge. Please take PPE with you if you feel that you need it when out on your activity.

Medals are subject to availability and will take 5-7 weeks to arrive to the 'Bys Vyken House of Creative Arts'. Medals should arrive to UK runners by early October and everyone outside of the UK by mid – late October. Please allow extra time due to the ongoing pandemic and the delay in expected delivery times.

These terms & conditions were assembled by the Governing Event Director of 'Bys Vyken Events & Cornish Trails', David W J Andrewartha.

We thank you for taking the time to read. Enjoy your adventurse!

Love,

Dave, Sally, Wally & Clydey x

SNOOD (DONATIONS OVER £10GBP OR FOR PURCHASE)

RAR MAKEL EAEULR



EXCLUSIVE EVENT MEDAL FOR All Finishers







BESPOKE BIB NUMBER WITH Your Name

THANK YOU & GOOD LUCK, LOVE CLYDE XX

