

# 2024 Webcast 2

## Keep on Running!

### Jo Chats With Steph Webb

Welcome to our second webcast in the series looking at a wide variety of topics of interest. Today I'm delighted to introduce Steph Webb, with whom I'll be discussing her reasons behind and methods of fundraising for AMEND.

If you've ever watched our patient experience films about MEN1, you will probably recognise Steph from these. Most recently, Steph has begun an extensive running fundraiser for the charity, so we'll look at how, with a rare endocrine disease, she has gone about training for that, as well as how it's all going.

#### **Can you tell us a bit about your endocrine condition and how that affects you day-to-day?**

So, I have something called MEN1, multiple endocrine neoplasia type 1, so there are multiple types, but I have type 1. It predominately impacts people in the pituitary glands and the pancreas and the parathyroid glands. I was originally diagnosed around 10 years ago because I had elevated calcium levels and parathyroid levels. I've had a total parathyroidectomy since then, so I'm now calcium dependant and have to take calcium daily so I'm constantly monitoring that to make sure I'm topped up so to speak. So that's the biggest way it impacts me, I do have a pancreatic lesion as well and liver lesions, I am on watch and wait for those, but I've got to be prepared and be aware that something could happen with those at any point.

#### **So, your calcium levels are the thing that are kept a close eye on at the moment with regards to your day to day life?**

Absolutely, so because I take calcium on a daily basis, I have to make sure that I am not overdoing it because you don't want to have too much calcium, but you also want to make sure you have enough. I have experienced when you don't have enough and it's not pleasant. It can be life threatening and it's painful to be perfectly frank as well. It's one of those things that you want to make sure that your levels are on point at all times as much as you possibly can. You have a little bit of leeway and flexibility with what that range can be, but a lot of the times when you are outside that scope it's hard to get back in that range, so you want to make sure that you are within that range at all times. A lot of times I have to make sure that if I am starting to become symptomatic, if I start getting tingling in my fingers I have to make sure that I have calcium nearby to take and it's not just the calcium that you can get over the counter, that might do a little bit of the job to try and tide me over but actually I need extra strength calcium that's specifically formulated and designed to work my body and my condition.

#### **So, it's a little bit of a juggling act but you decided to do quite an extraordinary fundraiser for AMEND this year so why don't you tell us a bit about your running goals this year?**

It spiralled basically, that's what happened. I started running last year and when I say last year I mean the very end of last year. I think I started running consistently in October and I was doing, maybe a couple of miles a week so it wasn't even that much but it's different for everybody but for me that was quite a lot. It was one of those, I thought you know what, let me try and do this. I used to play sport when I was younger and all of that and I missed having some kind of community, I'm American, you can tell by my accent, but I live in England so it's quite nice to have found a bit of a community by taking up running. I wanted to participate and challenge myself, so I thought I'll sign up for a 10k and then I saw that AMEND advertised that there are places for the Great North Run and I thought that's like the largest half marathon in the world I think, either in England or the world or something like that. I thought how amazing it would be if I was able to do that and what an achievement, I would feel in myself being able to do that. I thought, hey, I'll do that, let me contact AMEND and see if I can have one of their places. I was able to get one of the places and the fundraising goal was £200. By the time I had heard back from AMEND I had already decided, 'you know what? I live in Leeds, Leeds is local - let me try the first half marathon doing the Leeds half marathon and that way if I'm able to do the Great North Run, I will know at that point'. Then I realised there's the Leeds 10k as well and I thought that could be really good training for the Great North Run, let me sign up for that. So, while all these sign-ups were going on I then heard back that I got the place from AMEND. I thought, 'nobody is going to donate up to £200 for me to do this one race when I've already done a half marathon at that point and a couple of 10ks so let me just dedicate all my races'. Anything I do this year I have decided to dedicate to AMEND and always wear the AMEND logo on me at all times so that I am constantly raising awareness and hopefully raising funds as well. I thought 2024, why not shoot for the stars and try to raise £2,024! So that's kind of how it's all developed. I'm about 35% of the way there, I'm not sure that I will hit my target, but you know what, you have got to reach for the stars and the more awareness you raise, the more money that you raise it actually impacts me directly and I appreciate that, so anything I can do I want to.

**That's absolutely fantastic and you really have jumped in literally with both feet into the whole running and fundraising sphere for this year which is extraordinary. Thank you very much for supporting AMEND as well throughout the year and I hope maybe people will see this and will be inspired, if not to get running, then to donate to your fundraiser as well which would be amazing.**

I'd welcome that too. I appreciate the opportunity that AMEND has given me to actually do this, not just because of the Great North Run, but I'm also now doing the London 10k with an AMEND place as well. The support that AMEND provides me through community involvement events (we had a local meet up here near Leeds in Harrogate and I've met some other people with my condition, I've met some other people with similar conditions) that's what drives me and that's a huge motivation for me. It's my way of trying to say thank you and it's my way of trying to give back as well.

**That's lovely, it's another little family isn't it. My next question is when you are thinking about your calcium and your condition generally, has that affected how you have gone about training and how you do the runs?**

Absolutely, because you have that fine balance about how much calcium you need or having too much, one of the things you do as a runner (I consider this endurance running for me because I've never really done this mileage before) the more you run the more electrolytes you lose and obviously calcium has a big part to do with that, as does magnesium and actually when you take calcium you need to balance with magnesium, you need to balance with vitamin D, you are constantly trying to play that balance act. When you are trying to top up with electrolytes you have to be careful what ingredients they have in it. Any kind of fuelling I take on, so something that is heavily carb related I need to make sure that it doesn't have additives that might impact other aspects. Then I also have to worry about what my hydration looks like if I am taking on electrolytes

does that then have too much if I have just taken my medicine before a run, so yes its quite impactful you have to do a lot of mental maths trying to work it all out especially mid-race or mid-event it's not fun!

**So you are happy to stop part way and sort of think about it and adjust what you are taking in?**

Absolutely, that's the safest way of doing it to make sure but that does mean I might have a slower time than someone else my age, my ability might be able to do. I might have to actually physically stop and go I can't read that because I am getting older. Ok that has that, and I need to make sure I have this. Like I said I do try and pre plan a lot of it, so I am not out there in the midst of a run, but it does mean that I typically have to carry more with me when I'm out. I like to have a little pocket-sized store of calcium with me at all times, sometimes in my running vest you can hear it's clinking, it's really annoying if you are on a long run but it's making sure that I am putting myself in the best position I can be should something go wrong. I wear a medical badge as well so if I were to have some kind of incident or episode at least I would have medical badge on my bracelet so if an emergency service had to look at me, they would immediately see that I was calcium dependant and we need to check her levels, we need to make sure she is OK. It's those sorts of things that I have to worry about that not all other people do. I fully think that everybody should have some kind of medical ID even if it's just in case of emergency. But then when it comes to the typical mental juggling, the mind maths game of electrolytes and balancing everybody has to go through that but not everyone has to go through it to the same extent. What I do is the same as everyone else plus 10.

**I guess it's just being as prepared as can be so you can just go and do it.**

Absolutely, it's one of those annoying things as well that I don't feel comfortable not being in a running vest, I don't always necessarily want to wear a hydration vest but I'm a slow runner, if I'm on a race and they pack up the hydration station and I haven't got there I have to be prepared I have to have something on me at all times so I have to have that vest it could save my life.

**I did read something somewhere recently that if you are running a 10k you are already in the top 5% of all runners! It doesn't matter how quickly or slowly you go. It's the taking part and it's the challenge of getting to the end.**

Absolutely, I've joined a running community and it's one of the things they talk about – it's a fairly inclusive group. One of the things they try and drill into you is that it's about lines and not times. It's about making sure you cross that finish line in a healthy way - that you can cross it rather than trying to overdo it and overexert yourself and you don't even finish.

**Very sensible advice, when particularly you've got an existing condition that needs to be taken into account. Are there any days when you go, 'not today'?**

Every day! The only reason I started running in the first place if I back up that far, I was having some symptoms that were, I don't know how to explain it really, but effectively I was having some symptoms which could indicate that one of the tumours has grown and because of that I thought I need to be careful about what I eat, what I do, because if I have to have surgery I want to be in the best position I am in if I have to go under for any reason. Because of that it kind of spurred me on, thankfully everything seemed stable, and it was potentially due to over medicating on something else but actually I started enjoying it but the only reason I would go out there was because I know I need to do it. Eventually I have found a love for it now, it's still hard, I mean I'm not motivated to get out. You could say I'm motivated because I am accountable. And one of the ways I am accountable is that I am accountable to AMEND. I've taken on this fundraiser, I've announced it to the world, kind of

need to do it! I'm accountable to myself to make sure that I am staying in the best position I can be should I need to go into surgery. I'm accountable mentally, I know my mental health is better by doing this, because running actually helps clear the mind and helps ground you and I think I'm putting myself in a much better position by doing these things. I'm not motivated but I am at the same time it's what gets me out there.

**I think you have got a huge amount of motivation even if you probably don't feel that you do. It does take a lot of guts to get up, put your running shows on and just get out of the door.**

**You've already done one event, the canal canter 10k in Leeds.**

Yes, it was a local canal canter, that particular group of race providers (I don't know how you would describe them – I'm still fairly new to running!). They put on several events throughout the year, 5k, 10k, half marathon, marathon, ultra marathon. I have no desire to do a marathon or ultra marathon, I'm slow enough with my half marathon and I'm good with that for now! But because it was pretty much on my doorstep, I thought you know what let me give it a whirl that will be my first one and that will be kind of a teaser event and here I am signed up for 7 more events for the year, possibly more!

**I think its utterly fantastic, so your next one is the Leeds half marathon on 12<sup>th</sup> May, is that right?**

That's correct it's my first attempt at a half marathon. I've never done the distance; I'm looking forward to it but apparently, I've chosen the worst half marathon to do because its one of the hilliest so I not only have the challenge of hitting the mileage but I have the challenge of doing it at almost 200m throughout the course as well.

**So, if anyone is free on 12<sup>th</sup> May and wants to stand on one of the hillsides and shout you all the way to the top then you'd be pleased to see them?**

I'd gladly welcome that support, yeah! And please donate as well! I think that's one thing going back to motivation. One thing that has kept me going is actually not that people are drawn to my story but that people care enough, things are tight these days for a lot of people, we are in a cost of living crisis still and the fact that people are donating their hard earned money to support me, that's what motivates me and keeps me going and makes me think this is all worth it.

**Utterly fantastic, brilliant effort. So, if anyone is watching or listening to this and thinks maybe I should give it a go. Beyond getting a really good pair of trainers, where do you think they should start? Obviously, it's not going to be appropriate for everybody with all the diseases, it depends very much on your own situation, but for someone who is perhaps able to do it, where do you think they should start?**

The best piece of advice I could give is to run walk. If you run, you are a runner. If you run walk, you are a runner. Any movement that you do that is more than a walk is technically defined as being running so I think that anyone who wants to do anything, start slow. It's absolutely fine to go an 18-minute mile pace, that's absolutely ok to do. I started off at 16/17-minute mile pace and I've already brought that down significantly just by consistency and training. If someone actually is interested in this then give it a go. Why not! There is nothing that will hurt you by giving it a go, so try it, try it slow. Do what your body allows you to do and do what you want to do as well, don't try, and just push it because that's what everyone else does or that's what you expect you should do. Do what works for you.

**Brilliant, very wise words. Thank you so much for talking with me today, Steph, and I know I won't be alone in wishing you lots of success in your upcoming 7 running events, maybe more! Thank you for all you've done to support AMEND, its hugely appreciated.**

Thank you for the opportunity to even participate in one event, let alone allow me to fly the flag for the entire year. Thank you.

**Steph's Runs:**

- 16 March, Canal Canter 10k
- 12 May, Leeds Half
- 23 June, Leeds 10k
- 14 July, London 10k
- 19 August, Leeds Running Festival 10k
- 8 September, Great North Run
- 13 October, Manchester Half
- 20 October, Yorkshire 10 Mile