

## CASE STUDY (JULY 2021) WHY YOUNG PEOPLE LIKE 'BERTIE' NEED YOUR SUPPORT



"There is something incredibly powerful that happened as a result of the Muscle Help Foundation charity's 'Music 1.0' virtual Muscle Dream session; it has given our son ('Bertie', pictured above) hope, confidence and he has recognised what he is capable of.

We know as his family just how talented and capable he is, and now he knows and believes it too which is just wonderful to see."

Source: Ali, mum of 'Bertie', 9yrs

Many families have benefited from the support of The Muscle Help Foundation charity **during the pandemic** - the charity had been used to providing highly personalised, face-to-face wish fulfilment experiences, but the pandemic meant they had to pivot, **taking everything online** which has proved invaluable to its beneficiaries **during the lockdowns**.

One **virtual** *Muscle Dream* **beneficiary**, called **Bertie** (**9yrs**) with **Muscular Dystrophy**, and his family, took part in one of the charity's **digital experiences** focused on **music**. The family has a real love of music and prior to the lockdowns, attending music festivals such as Glastonbury and The Deer Shed Festival were regular dates in the family's social calendar.

Bertie's mum, who spotted the charity's **innovative**, digital wish fulfilment experiences on social media during lockdown, says:

"As soon as I saw that The Muscle Help Foundation charity had these online sessions available, I put in an application as I just knew it would be perfect for my son. We didn't know whether we would get a place, so we just kept our fingers crossed and happily we got accepted.

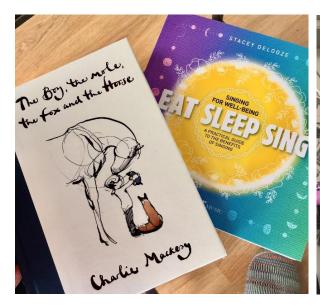
"Being able to access this online experience was incredibly important to 'B' and indeed, the whole family. Bertie has a real passion for music and drama, but the sad reality is that we have found it incredibly challenging to access inclusive music and drama groups even before the pandemic; they just do not exist, or our requests are ignored due to access issues which is very disheartening."



"These digital experiences from The Muscle Help Foundation were available at a time of significant stress and worry for us as a family; the pandemic had literally cut us off from all of the therapy we were used to being able to access for Bertie – everything literally came to a standstill due to the lockdowns. That was coupled with fear surrounding COVID-19 because at that time, we simply didn't know how vulnerable 'B' might be."

Bertie lives with a form of Muscular Dystrophy that has respiratory impacts which meant the family had no choice but to take the strictest precautions to protect themselves. His mum continues:

"There were so many unknowns at the start of the pandemic; it was a very worrying time and very scary. Bertie was in the process of getting some respiratory assessment as the pandemic emerged, but nobody knew enough about the virus back then, so we've been shielding throughout."





All 'Music 1.0' Muscle Warrior participants received a copy of: 'The Boy, The Mole, The Fox and The Horse' by Charlie Mackesy 'Eat Sleep Sing' by Stacey DeLooze

Everyone who takes part in a *Muscle Dream* experience with the Muscle Help Foundation charity is known as a *Muscle Warrior* and becomes part of a unique **'tribal' community**. Reflecting on the musical session itself Bertie's mum says:

"Our son felt loved, appreciated, noticed, nurtured and part of a community – it didn't feel like a digital session it felt really warm and engaging and there was lots of music and voice exercises; and lots of laughter too.

It was a safe space to express himself; it lifted his spirits and confidence during what has been a very lonely and isolating time for him and us. It was also a great day for the whole family - we all listened in, and the experience even included a food voucher which meant we all gathered round as a family straight after to enjoy a lovely meal and talked about how wonderful the session had been."



In response to hearing that wish fulfillment experiences like those provided by the Muscle Help Foundation have now been academically proven to offer long-term benefits for participants, Bertie's mum says:

"It really doesn't surprise me at all that the benefits of wish fulfilment activities extend beyond the experience itself. I know first-hand the positive impacts that 'B' has had from the music session; it has lit a real musical fire in him now and he actively wants to pursue more musical experiences.

He has even started to write and perform his own music and that comes directly from the confidence and empowerment he got from the session. I'm not sure he would have thought he could do it before, but he believes in himself now; nothing is going to stop him. There is something incredibly powerful that happened as a result of the session; it has given 'B' hope, confidence and he has recognised what he is capable of. We know as his family just how talented and capable he is, and now he knows and believes it too which is just wonderful to see.

We've even found a music and drama group he can start attending when it's safe to do so, and his school are also supporting his musical and drama interests now that we know it's an area he wants to pursue more.

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"There is a real gap in services and support for children like my son and it's vital that society is more inclusive of everyone, no matter what their situation might be. Charities like The Muscle Help Foundation have provided a lifeline to our family and others and are empowering children like our son Bertie - we need more of that.

And now it has been academically proven that the benefits of wish fulfilment experiences have long term positive impacts, we need to ensure more children can access these experiences."

## Special thanks to:

To Ali (Bertie's mum)
For agreeing to be interviewed & for providing consent

Mary Bawn of The LaunchBox A strategic marketing, digital and PR consultancy For interviewing Ali and for producing this case study More info: <a href="https://www.thelaunchbox.co.uk/">https://www.thelaunchbox.co.uk/</a>

