

# NICE Patient Expert INNOVATES

*Nick Hartshorne-Evans*

## Pumping Marvellous



**My first time in a hospital bed wasn't because I had broken leg or an appendicitis: it was because I had heart failure. At 39 that's a tough gig. After five weeks of trips to the GP, random courses of antibiotics and referrals to the weight clinic my wife forced our GP to admit me to hospital. I was so ill I couldn't argue my own case. After a week on the renal ward where they were determined I had hepatitis I was diagnosed with Heart Failure. After my upgrade to the coronary care unit my treatment began. My diagnosis of heart failure was caused by viral myocarditis, I had no underlying cardiac condition.**

Being told you have a diagnosis of heart failure sounds terminal. If you read most things on the internet then it tells you that the chances are you won't make it past 5 years post diagnosis and that the prognosis is worse than most forms of common cancer.

For over 11 years before the diagnosis I ran my own businesses and could have been described as a successful entrepreneur. I was recognised for my achievements both nationally and regionally and had all the trappings that success brings. It sounds as though it was easy but it really wasn't. When you run your own business you have to fight for every gain and every penny made. It's a tough world and you really learn on your feet. You need to be agile, resilient, athletic, determined, and confident, understanding that failure is acceptable and part of what you do. Understanding and assessing risk is important, losing money isn't the only risk you need to think about. Being a successful entrepreneur is time consuming as well so be prepared to not switch off, it's one of my traits that I have not been able to change. You are thinking 25 hours a day by 8 days a week about opportunity and plugging need, you don't switch off.

So these are the majority of traits of entrepreneur.

So you could say that when I made a life choice in June 2010 to start a small patient group with the purchase of a domain name for £9.99 I had all the key ingredients to bake a great cake. Nine years of corporate achievement, eleven years of being an entrepreneur and now thrust into the world of having to manage my heart failure. What a recipe for success, I always see the positive in most things.

So where was the need? When I was discharged from hospital there was no social or psychological support, nobody to share experiences with and nobody to talk to about having a diagnosis of heart failure. I had a fantastic clinical team but having a long term condition like heart failure isn't just about clinical interventions it's a lot more than that.

The Pumping Marvellous Foundation was born and is now the UK's patient led Heart Failure charity. What I quickly learnt was that being a charity meant we had to compete at every level for every opportunity. It was like owning your own business as everybody liked the idea of your product, wanted to be associated with the whole charity piece, it was nice to have a "third sector" ally, it satisfied the tick box managers very well, you've seen it, the one that says patients have been consulted, but the majority of those in the health system don't want the lid lifted off a box that they may not be able to close. Not the patient voice but the customers wanting to develop what their care and treatment looks like.

My time is spent winning friends and influencing diverse stakeholders to believe in what we believe in. Bringing the whole conversation together. Lots of people want to see us succeed and thrive as they inherently believe that the patient isn't just the menu but sits around the table to design the menu in collaboration with their multi-disciplinary team.

So how do you go about satisfying the need of a nation of patients who feel that they are 2nd class citizens and don't get the same level of support that cancer patients do even though they have a worse prognosis than the vast majority of cancers sufferers? How do you think they feel when nobody seems to know what heart failure is and they don't even have a voice? There are nearly a million people in the UK diagnosed with heart failure, it is the ultimate Cinderella syndrome and the Pumping Marvellous Foundation occupies the position of the first dedicated patient group in the UK to give these people a voice. Others say they have been representing heart failure patients for years but not at the patient level, the coal face.

So having such a large underserved population as a need that's where I saw the opportunity.

- The Pumping Marvellous Foundation is a unique charity. It has patient educators who are expert patients who make up our Patient Board. They all come from different backgrounds, different parts of the country and have different skills, company directors, managers, home CEO's, business owners etc etc but they have one thing in common they all want to put back into the system and they believe in what we believe in. So unlike your traditional organisational model adopted by 99.9% of organisations the Patient Board, the customers determine tactical activities and strategic direction and the operational team, myself included activates and makes those decisions visible. The Trustees manage governance. A truly patient driven organisation where the customers decide the agenda.

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Mbrings. It sounds as though it was easy but it really wasn't. When you run your own business you have to fight for every gain and

- How do you scale a movement rapidly? We are a new breed of digital charity and we crowdsource the majority of our information from our active global patient community. This is an unbelievable resource which enables patients to get actively involved in projects which we are working on. That involvement becomes a hugely effective peer to peer network for self-learning and support. An example of this was when patients over a 24hr period on our closed facebook group gave me the information to present to over five hundred cardiologists at a Heart Failure Summit in Barcelona in October 2015. I presented their opinions and shared my presentation with the community. If people give something they expect to see what you have done with their valuable nugget of information.
- Credibility has always been something we strive for therefore we are always on the lookout for mentors, sponsors and believers in what we are aiming for. As the foundation is about ensuring the best quality of life for people and their families having to manage heart failure you would have thought this would be everybody's objectives but it isn't, some people are just happy to build their own castle. Therefore we are very fussy about who we work with and therefore here is another lesson. The people who you work with closely, pick wisely. You may not be aligned on everything but there will be a fundamental thread you have in common.
- Life is one big transaction. Imagine asking a healthcare professional to sell self-management to a patient? So see your relationships as transactions in their most rudimentary form, you give me something and I'll give you something. Now that sounds simple enough but let's look at this differently. A good entrepreneur knows what you want before they have engaged with you. Now they may not have rationalised your response perfectly but they will have a good idea what could make that transaction work. So the skill is to know what you want and know what they want and that this will create an acceptable transaction. A good example of this is our relationship with NICE. The need was that NICE struggled to engage with any patient groups around heart failure. Patient involvement in NICE's work is well documented and therefore was a need. Our relationship with NICE is that we are always there to support them in technology appraisals and guidelines, we never let them down and give a depth of patient involvement that understands the challenges that NICE has in its role. By doing this we build a strong relationship and therefore we have strong position as a patient group to potentially influence guidelines and technologies that could have a positive impact on the quality of life of heart failure patients and their families.
- Always ensure that you share your successes with your stakeholders. At your peril think that your success is your success only. Success breeds success.
- Timing feels like everything. Being in the right place at the right time is usually the habitat of the entrepreneur, see the opportunity and grab it. Be prepared to be flexible.
- Speed, accuracy and delivery are the hallmarks of an entrepreneur. Speed to win the idea, develop the idea which exceeds expectations and deliver it on time and to budget. I manage people's expectations very well.
- Are you a mower or a grower? I am a grower but I also enjoy sowing the seed, germinating it and seeing it flourish
- To get something done in business you generally have to have a penchant for managing people. Pick your team well and always value their input. Allow them to make mistakes but manage that risk don't make it visible to the outside world. Hire people who believe in what you believe in, these are our patients. U-Turns are OK if it means a better solution.

I do what I do because I am passionate about fixing some of the challenges ahead for heart failure. Everything we do at the Pumping Marvellous Foundation is about challenging the status quo, we believe by challenging the status quo we can change, for the better the quality of life of heart failure patients and their families.

People are believing our goals.



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