Dragon's Dare

Spina Bifida
Hydrocephalus
Scotland

DO YOU ACCEPT THE DRAGON'S DARE?

Duncan Bannatyne OBE, Patron of SBH Scotland

A true entrepreneurial challenge;
Making something out of nothing!

In 2015, with the support of SBH Scotland's Patron, Duncan Bannatyne OBE, Spina Bifida Hydrocephalus Scotland launched a new and creative business fundraising platform - The Dragon's Dare.

In 2016, the Dragon's Dare is back... Will you accept the challenge?

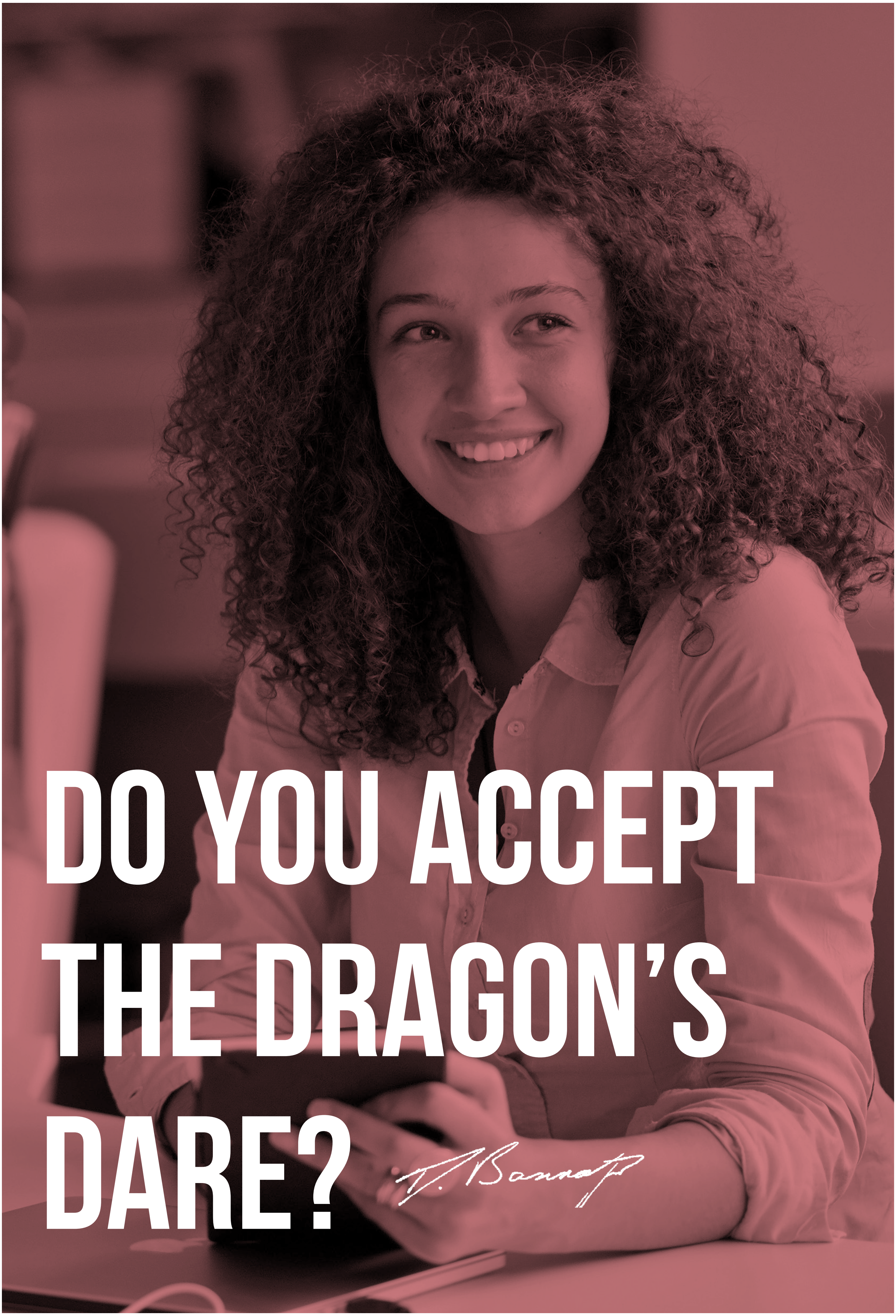
The Challenge

Start with £0 and make as much money as possible.

Using your business acumen, hard work and entrepreneurial flare you will not only be able to gain valuable skills and experience, but raise much needed funds for a very special Scottish charity.

Duncan Bannatyne OBE

Duncan Bannatyne OBE, Scotland's best known Entrepreneur, bestselling author and star of the BBC series Dragons Den became involved with SBH Scotland after attending a Gala Dinner in 2007. Duncan generously supported this event in 2007/8 and was keen to discover more about the work that SBH Scotland carried out in Scotland. Duncan officially joined as Patron in February 2009 and has been working on projects that will help fund this vital Scottish Charity. See more at: **www.sbhscotland.org.uk**



DO YOU ACCEPT THE DRAGON'S DARE?

T. Bonnet

WHY SPINA BIFIDA HYDROCEPHALUS SCOTLAND?

The Scottish Spina Bifida Association was founded in 1965 by a small group of enthusiastic parents who each had a child with spina bifida and/or hydrocephalus.

Today

50 years on, we are a registered Scottish charity, now known as Spina Bifida Hydrocephalus Scotland (SBH Scotland). We employ specialist staff who work across Scotland and from our Family Support Centre based in the central belt of Scotland. Our staff provide a multifaceted service offering a life-time commitment of information and support to all those affected by spina bifida, hydrocephalus and allied conditions, across Scotland.

Since 1965, we have been almost entirely self-funded but thanks to donations from supporters past and present our services have been able to flourish. We are now in a position where we successfully provide more support than ever before to over 3500 children, young people, adults, their carers and families across Scotland.

None of our support would be possible without fundraising and every year we have to raise nearly £1 million. With less than 1% in government funding we remain grateful to all those who have, and continue to, support us.

Glasgow Caledonian University is where many of our fundraising team completed their further education so we know how pioneering the students are. We need your vision and drive to help us raise £20,000 to help continue our work.

By taking part in the Dragon's Dare you will help fund specialist family support workers who will provide intensive support to families and individuals when they need it most.

Thank you for supporting SBH Scotland.

You're allowing us to give hope.

CAN YOU IMAGINE BEING BORN WITH A COMPLEX LIFE-LONG DISABILITY?

THERE IS NO CURE AND NO KNOWN CAUSE.

Spina bifida is a fault in the spine that develops in early pregnancy. The majority of those born with the disability will be paralysed from the waist down, be affected by bowel and bladder complications and will be lifelong wheelchair users. The individual, despite numerous operations, may require lifelong support and have multiple complex support needs, ranging from intermittent to 24/7. Additionally, many will also have hydrocephalus, a condition that affects the brain and how it functions. Hydrocephalus can occur at any age as an allied or main condition but is more common in babies/infants and can lead to social, emotional, cognitive and behavioural difficulties.

Spina bifida and/or hydrocephalus can affect any pregnancy regardless of the mother's age, ethnicity or social background. There is no cure and no known cause.

For the families, a diagnosis of spina bifida and/or hydrocephalus is an emotionally shattering experience, in an instant destroying parents' cherished dreams and replacing them with a life of worry and stress, financial uncertainty and daily challenges. Few parents or carers have the strength and resilience to handle all the situations they will face alone. As the child transitions into adulthood, the challenges continue for the family and the individual on a daily basis. Things we take for granted such as living independently or achieving vocational or educational qualifications, for most, doesn't occur without specialist support.

Stephen had a dream to go to university but he soon found that making the dream a reality was going to be more difficult than merely getting the grades!

Stephen is 18 years old and has spina bifida and hydrocephalus. His spina bifida means that he is a life-long wheelchair user with bladder and bowel complications and because of his hydrocephalus he also has cognitive issues.

In spite of his hydrocephalus, Stephen worked hard and achieved academically, so it was time to look at universities to see which one he wanted to attend.

Stephen explains, "Because a lot of universities were built prior to disabled access being a legal requirement, many of them weren't an option for me as mobility would be an issue. I went to a few open days and on arrival found that I wasn't able to access some buildings, or that the classrooms were laid out in such a way that I would always have been sitting right down at the front. Being a wheelchair user makes you stand out enough as it is; I just wanted to fit in. I also found that some corridors weren't very wide and when they were busy, getting through them was a nightmare."

Stephen got a place at university studying Business Management but, as anyone who has recently started higher education will know, there are a few initial culture shocks! However, for those with complex disabilities there are many other challenges that the majority of new students will never have to worry about.

Prior to university life Stephen had always been reliant on his parents and family to look after most of his everyday basic needs, including assisting with showering, getting dressed and going to the toilet. So the transition to independent living was a huge change in itself.

"The move to university wasn't the easiest of transitions. I was used to the same people helping me throughout the day. Now I've had to approach new people for assistance and I still find it quite embarrassing asking someone for help with things that are basic for most people. Moving to university was definitely daunting at first. In school I had the same four friends all the way through, we were in the same classes and knew how to work well together. But with group coursework in university, I was thrown into meeting new people and having to work with them straight away - that really threw me off. Thankfully I have made a few good friends in my year who I get on really well with but if I had not met them, I really don't know what I would have done."

SBH Scotland focus on early intervention, which allows a smoother process for those making big transitions in their lives, either in healthcare, living independently or in education. Your ability to fundraise through Dragon's Dare will not just have an impact on your grade, but could have a direct impact on young people throughout Scotland by enabling SBH Scotland to add quality to life, everyday. Thank you.

FYI

SPINA BIFIDA AND HYDROCEPHALUS - THE FACTS

28 DAYS

- Spina bifida (Latin for "split spine") is a Neural Tube Defect which occurs very early in pregnancy. It is caused by the failure of the neural tube to close properly and the fault occurs in the first 28 days of pregnancy.

- Spina bifida occurs as the vertebrae (bones of the spine) develop; they would normally grow and close securely around the spinal cord and nerves. When spina bifida occurs, one or more vertebrae do not close properly and become "split" resulting in the spinal cord and nerves becoming damaged. The extent of damage varies depending on the nature and location of the "split". Often the baby is born with part of the spinal cord formed outside the body and an urgent operation is required within hours of birth to close the spine.

- The majority of those affected will be paralysed from the waist down and will also suffer severe bladder and bowel problems.

- In addition 80% of those children born with spina bifida will also be affected by hydrocephalus (commonly known as "water on the brain"). The brain and spinal cord are bathed in an essential fluid called Cerebrospinal Fluid (CSF) which normally drains from the brain via the spinal cord. When the flow of CSF is interrupted or pressurised as a result of the damaged spine, it results in a build up of fluid in the brain known as hydrocephalus. The build up of fluid causes the ventricles in the brain to swell and puts pressure on the surrounding tissue. Hydrocephalus is life threatening but may be controlled via the insertion of a shunt that helps drain the CSF. This is another urgent operation that can take place within a couple of days of birth.

80

ONE
THOUSAND

- Hydrocephalus is not only associated with spina bifida. There are many reasons that hydrocephalus might occur. Often it is secondary to another condition that has affected the brain or the central nervous system such as meningitis, premature birth or a tumour.
- Hydrocephalus often causes numerous neurological disorders including problems with hearing, sound, impaired concentration and organisational skills. Different allied conditions can increase the type and severity of difficulties experienced.
- Both spina bifida and hydrocephalus can affect any pregnancy regardless of the mothers age, ethnicity or background. Both conditions cause lifelong complex disabilities of which there is no cure.
- As a result of spina bifida occurring in the first 28 days of pregnancy, once a woman discovers that she is pregnant, the condition may already have developed.
- Taking folic acid at least three months prior to conception has been proven to significantly reduce the risk of spina bifida in an unborn child.
- NHS Scotland guidelines state that every woman who might become pregnant should take daily folic acid supplements as a precaution. Folic acid is also known as vitamin B9.

VIT
B9

The Numbers:

- Spina bifida is one of the conditions that prenatal scans can usually detect at the 20 week pregnancy scan.
- Spina bifida is particularly relevant for all sexually active women in Scotland as historically Scotland has had a higher prevalence of Neural Tube Defects (NTDs) than the rest of Europe (Eurocat 2010). Spina Bifida is the most common NTD.
- The latest figures available in Scotland confirms that over 1 in every 1000 pregnancies are affected. (SPIMMR:2011). Across the UK at least two babies are conceived with a NTD daily.

20
WEEK

WHERE TO BEGIN?

For ideas and tips on raising funds please download our Fundraising Toolkit at www.sbhscotland.org.uk/dare here you will find checklists and top tips on everything from legally fundraising and running an event to staying safe while you do it. But our top ten Do's and Don'ts are…

Event Planning Checklist

1. Download Spina Bifida Hydrocephalus Scotland 'In aid of logo' from www.sbhscotland.org.uk/dare and clearly display this on all materials with our registered Scottish Charity number SC013328 so people can clearly see who you are raising money for.
2. Do you need fundraising materials or some advice? Contact the SBH Scotland Fundraising Team on 03455 211 600.
3. Keep your costs low, if you can get the tools, materials and prizes (if required) for free then that is fantastic! If something isn't essential to the success of your challenge then a good rule of thumb is to leave it.
4. Publicise your event/idea/product. Use social media, word of mouth, posters, email, blogs and websites – basically use anything legally at your disposal.
5. Make sure you have all relevant licences required for your event such as music, sale of alcohol, extended hours and provision of food and drink.
6. Please don't hold collections in the street, house to house or in any public place without prior written approval from the local authority. A licence is required for these types of collections.
7. Please don't collect on private property such as a supermarket or shopping centre without first asking permission from the owner – this may need to be done in writing and in advance of the day you choose to collect.
8. Please don't organise a raffle or lottery without first contacting the SBH Scotland Fundraising Team as a gaming licence may be required for this type of activity. This does not impact on raffles where tickets will be sold on the same day that the raffle will be drawn and in the same location.
9. Please don't act as a representative of SBH Scotland or present yourself in a manner which could be construed as you being a representative of the charity – we really value you as a volunteer fundraiser and are very grateful to you for all your hard work but unfortunately we are unable to authorise you to officially represent SBH Scotland.
10. Please don't let anyone under sixteen or vulnerable adults collect money, all collectors must be over the age of sixteen. Vulnerable people should be accompanied by another adult – this is to ensure their safety.

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Having a baby with spina bifida or hydrocephalus is not the end. Just the beginning.

SBH Scotland.
There for the journey.

Help us make a difference.

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