

## The Silent Bleed - a charity from Aldershot, making a difference across the world.

### What can happen when a small group of people decide to fight back against an incredibly rare disease?

It's estimated that the condition, Superficial Siderosis affects just one person in three million. Symptoms often start with bad balance, hearing loss and sight problems but it will likely go on to affect bowel and bladder function, cause dementia and a whole raft of other debilitating issues. It's serious and degenerative but few people know about it. Local charity, The Silent Bleed, want to change this.

### Raising money, having fun

The charity has organised a number of local events, which couldn't have taken place without the solid generosity of local businesses. Gifts have included tombola prizes like meals for two and bottles along with proceeds from in-house events like the weekly meat raffle.

The first this year was at the **Albion Tavern in Farnham on 3<sup>rd</sup> February**, when the Missy Nelson Band brought the house down for a one-night Silent Bleed party. The band, the staff, the kitchen and the locals came together to enjoy food, music and fun – and raised £500 in the process.

**The most recent event was on Monday 5th March**, when patrons of the **Six Bells, Farnham** dug deep for a **charity pub quiz** with another stunning total of £250 raised. The Silent Bleed team were proud to be joint winners on the night but the reality is that everyone in the Superficial Siderosis community shares in the success, as another cheque to the centre of research, Dr Levy at Johns Hopkins in Baltimore is due to make its way across the Atlantic next week - **this time for £1,000, which is around 1,390 in US dollars.**

The charity also supports the research of Professor Werring at the Stroke Centre at UCL, Queens Square, London.

### A cruel condition for survivors only

A history of stroke, brain trauma or neuro surgery can cause a tiny, silent bleed and the residue this leaves behind effectively destroys nerve cells and affects the way they work. It's a degenerative condition.

Established in 2016 by Jason Roberts, The Silent Bleed is already making a difference. In touch with pioneering doctors in the USA as well as London, the charity is raising money for research. It's also an important hub where sufferers can network, find answers and access specialist help. Raising awareness is also key: the charity believes that lack of information is affecting diagnosis rates and therefore research and funding for treatment.

There is only one pioneering drug that's known to help stem the progress of the condition and applications for funding to regional NHS boards are currently routinely turned down. Appeals are usually upheld but the charity supports sufferers through the process, which is often distressing.

### Making headway

Linking with bloggers, doctors and a strong Facebook community, the group registered as a charity in 2016, established a website (which is currently being overhauled) and the aim for 2018 is to found satellite groups around the world. Through research, awareness and networking, the charity hopes to relieve the panic, suffering and confusion that can arise when someone is diagnosed from this rare, cruel and life-changing condition.

More and more people get in touch with the charity every week and in order to help them, the team needs to grow. Members of the press, anyone who'd like to host a fund-raising event, or generous people with skills that they'd like to lend to this small, friendly charity with big dreams, should call Amanda on 07870 625357 or visit the website at [www.thesilentbleed.co.uk](http://www.thesilentbleed.co.uk).