

**An update on fundraising for 2018-29 District Chairman
Gill Scott's chosen charity
An extract from the National Amyloidosis Centre News
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'Fundraising News

Inner Wheel Clubs *By Gill Scott*

My name is Gill Scott, and I am a member of the Inner Wheel Club of Clevedon. This year (2018/2019), I am also the District Ten Chairman, responsible for clubs ranging from Pershore and Worcester, across to Leominster, Hereford and the Forest of Dean, through Cirencester and Gloucester, and down to Clevedon.

It is customary for the District Chairman to visit and speak at all these clubs, giving any donations to her chosen charity for the year. It was not difficult for me to select a charity for my year because my husband died of cardiac amyloidosis.



Pete died because, sadly, there was, and remains, no permanent cure for this rare disease. Pete was also too ill by the time of his diagnosis to receive care from the team at the Royal Free in London, but my daughter, Emma, and I kept in touch with the team, and decided that we really wanted to help raise funds for a cardiac MRI scanner.

So, after Pete's death, family, friends and my Inner Wheel buddies worked really hard to raise funds towards the cardiac MRI scanner. I am so pleased that this machine is now in situ at The Royal Free Hospital and it has already given the benefit of early diagnosis, and therefore improved quality of life, for many patients. Emma and I were touched to be invited to the official opening of the scanner in

2016 by The Princess Royal, and were pleased to meet staff and patients on such a lovely occasion.



I did say at the fundraising concert for the scanner that I would not be asking for support again - but life moves on, and I have kept in touch with Beth Jones and Professor Hawkins, and found they were once again trying to raise enough funds, this time to purchase a tissue testing machine for the Amyloidosis Centre. We just had to get behind them again because, whilst nothing can be done to change the outcome for Pete, many people could receive an earlier diagnosis, and have more time with their loved ones, if this machine could be purchased.

I have raised just over a thousand pounds from speaking at Clubs and received a substantial personal donation as well. With Emma, and the amazing support of Inner Wheel District Ten, we staged a charity concert at Christchurch,

Clevedon, to build upon this figure even more. The concert, held on 18 May, featured performances by local choirs - Portishead Sound, The Chandeliers, The Me Time Singers and Generation Vibe (a choir made up of young people aged 8-14



years), all of whom generously gave their time and talents. Catherine Smith and Wendy Sergeant (who was formerly an amyloidosis nurse at the Royal Free), arranged and produced the concert for me, and it went brilliantly.

Inner Wheel Clubs across the District donated some amazing themed hampers which we auctioned, there was a raffle, with some generous prizes donated by local companies including Nuffield Health, and a staggering sum of £2,096.50 was raised. I also received a further donation of £200 bringing the total amount raised to over £3,200.00!

I have been clear from the outset that whilst funds are desperately needed, awareness of

amyloidosis is a key element in understanding and treatment of the disease. Whenever I speak to a group of people, I ask them to consider talking about amyloidosis to just one person. This costs nothing, but is priceless in spreading this essential information.

Our lives will never be the same, of course, and we miss Pete every day, but Emma and I know that our efforts to raise awareness and funds are exactly what he would have wanted us to do.

Life and time with loved ones is a precious gift, and we hope in some very small way to have helped the Amyloidosis Team to enable patients and their families to enjoy more time together.