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# Annual HEAL Newsletter

‘HEart and the ALexander Jansons Foundation’

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Patient information and research news from the Alexander Jansons Foundation Charity working with Royal Brompton & Harefield NHS Foundation Trust.

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For further information visit our website

[www.alexanderjansonsfoundation.org](http://www.alexanderjansonsfoundation.org)

Or if you are up for a challenge why not organise your own fundraising event with our help and support contact

[patricia@alexanderjansonsfoundation.org](mailto:patricia@alexanderjansonsfoundation.org) 01494

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### Welcome message from Andy Jansons

The Foundation was launched after the death of my son Alexander from Myocarditis in July 2013. He was 18 years old.

We have pledged a minimum of £80,000 per year to fund research into the causes, prevention and cures for Myocarditis. With this research we will save lives in the future.

Within the UK every year several thousand patients are diagnosed with this condition and one of the tragic consequences is that it can affect otherwise very healthy people. The Foundation strives to gain insights into the scale of this problem and potential mechanisms. Royal Brompton Hospital aims to look at early markers to guide who may be at risk of developing the condition or of adverse outcomes.

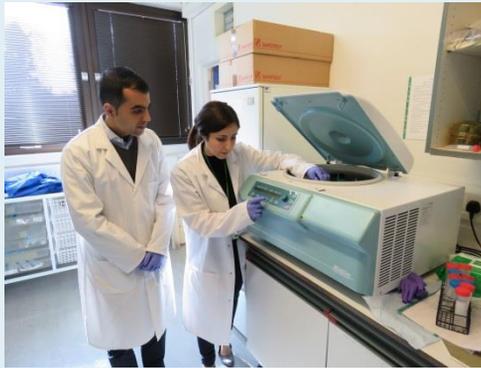
What are our overall goals?

- Early detection of those at risk
- Early initiation of treatment
- Improving clinical outcomes
- Awareness
- Connectivity via our website

We have decided to produce this newsletter to provide more information about Myocarditis to the general public and give an update about the research being funded by the charity.

All our funding comes from donations and charity events and the total amount goes directly into research.

# Annual HEAL Newsletter



## Research Update from Royal Brompton & Harefield NHS Foundation Trust



New centrifuge bought with funds from the Alexander Jansons Foundation

### What are we doing?

We are launching a prospective clinical study of patients presenting with acute myocarditis to identify new strategies for early diagnosis and risk prediction, which represent some of the main challenges with this condition. We aim to develop new cardiac MRI imaging sequences alongside blood tests to detect new biomarkers and genetic analysis in our patients. We envisage that the combination of these powerful techniques will improve early diagnosis and identify the 'high-risk' individuals requiring closer monitoring and treatment.

### New centrifuge

Using part of the funds from the support of the Jansons Foundation charity we have now purchased an additional centrifuge machine to spin blood samples to extract serum and plasma for discovery of new biomarkers and genetics in myocarditis. This centrifuge will be based at Harefield Hospital to allow increased recruitment at this site.

### Patient Recruitment

Patient recruitment at Royal Brompton and Harefield Hospitals has previously been focused on patients who have developed dilated cardiomyopathy (the chronic form of myocarditis). However we are now moving our focus to recruit patients in the acute phase of myocarditis when it is first diagnosed, in order to predict novel biomarkers at baseline, 3 months and 1 year after initial presentation.

For this we are working with specialists from Cambridge and University College London to design the multi-centre study recruitment plan. Once ethics approval is in place, patient recruitment will hopefully commence in June 2016.

### Meet the team:



From left to right:  
Dr Sanjay Prasad (consultant cardiologist), Dr  
Amrit Lota (clinical research fellow), Rebecca  
Wassall (cardiovascular research nurse)

To find out more information please contact the [Alexander Jansons Foundation](#).

## Questions & Answers with Dr Prasad



### 1. What is myocarditis?

Myocarditis means inflammation of the myocardium. The myocardium is the heart muscle. There are various causes but it is usually caused by a virus. Symptoms can range from no symptoms at all, to life-threatening heart failure. Many people with myocarditis recover completely but it can cause serious problems and even death in some cases.

### 2. What are the causes?

Myocarditis can affect anyone and occur at any age. There are various causes; many are mild and some are serious. Causes include the following: viruses, infections, alcohol, radiation therapy, as a rare side-effect of some medications, with certain inflammatory conditions such as systemic lupus erythematosus.

### 3. What are the signs and symptoms?

These can be variable but include chest pain, fever (raised temperature), a fast heartbeat - faster than usual for a normal high temperature (fever), an irregular heartbeat, tiredness, shortness of breath.

We would like to acknowledge the BHF as an important source of information for myocarditis



### 4. How is myocarditis diagnosed?

A number of tests including a heart-tracing (ECG), blood tests for a protein leaked from damaged heart called troponin, and an ultrasound scan of the heart (echocardiogram) may also be arranged. You may also have an MRI to show how your heart is being affected.

### 5. How is myocarditis treated?

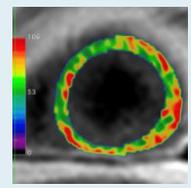
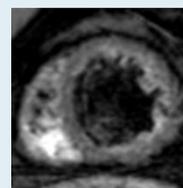
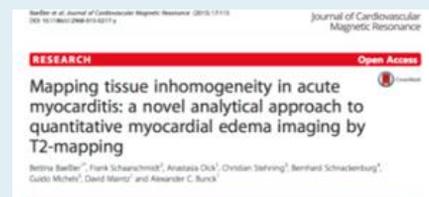
For the majority, guidance is to rest, avoid heavy exercise and take painkillers when needed. At the moment, there is no specific treatment that can tackle the viral infection. Steroids have been tried but are not found to be effective. Occasionally other treatments are used. These include:

- Medication to treat heart failure or irregular heartbeats.
- A pacemaker if certain irregular heart rhythms develop.
- Antibiotic medicines if the cause of the myocarditis is a germ (a bacterial infection).
- Steroid medication if the cause is giant cell myocarditis.
- Avoiding alcohol.

#### Latest research in myocarditis

[“ Mapping tissue inhomogeneity in acute myocarditis: a novel analytical approach to quantitative myocardial edema imaging by T2-mapping ” Baeßler et al \(2015\)](#)

Researchers in Germany have defined cut-off values for a new cardiac MRI technique called T2-mapping, which brings this early diagnostic tool a step closer to routine clinical practice. [Left image: standard cross sectional image, right image: superimposed T2 colour map highlighting areas of inflammation].



To find out more information or if you have a question for Dr Prasad for the next newsletter, please contact the [Alexander Jansons Foundation](#).

### Matthew's story

My experience with myocarditis has been a frustrating and frightening process that has required huge amounts of patience. As a 19 year old it is something you never expect to face. I experienced breathlessness and chest pains at my university halls and had to call an ambulance myself. The uncertainty when I was first admitted was perhaps the most disconcerting element of myocarditis. There seemed to be an endless monitoring process, with little hard facts or answers, as not a great deal is currently known about myocarditis. Despite this, the care I received from Dr Prasad, Dr Lyon and all Royal Brompton & Harefield staff was superb.



Moving forward, having been released from the RBH after various MRI and echocardiogram tests I was bound by a number of restrictions for 3 months. This included only moderate exercise and minimal alcohol intake as well as anything that would raise my heart rate. This was an extremely frustrating time, not being able to go out and enjoy the usual activities at university. But the overriding emotion was of worry and anxiousness as I was waiting to go back to Royal Brompton Hospital to see how my scar had healed.

Later on in the year, after these results had come back all clear, I had a small reoccurrence. Following additional treatment, the initial cause of my condition went completely, but I have some small scar tissue as a result and so I now take regular medication a year on from the initial onset of myocarditis. I still suffer mild symptoms but monitor these with AliveCor, a handheld ECG.



I have essentially made a full recovery now and exercise and alcohol consumption is only slightly restricted, with my daily routine almost back to normal.

To sum up my experience of myocarditis, I would say that I have had to deal with the fear of the unknown and possess a huge amount of patience, as a key part of the treatment is to monitor any changes in the performance of my heart over a period of months, rather than there being a quick fix solution or one-off operation. It has also been quite stressful, as it is only natural to worry more about a potential problem with your heart (as opposed to one involving less critical organs). Throughout the whole process, the support and advice of Dr Prasad and his team has been instrumental in helping me deal with everything I have had to face. *(Matthew, 19 years old)*

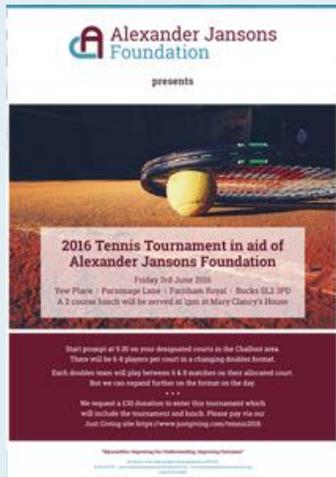
#### **Useful patient websites:**

<http://www.c-r-y.org.uk/>  
[www.bhf.org.uk](http://www.bhf.org.uk)  
<http://www.myocarditisfoundation.org>  
<http://www.cardiomyopathy.org/>

#### **Patient information day:**

September, 2016 date to be confirmed  
To find out more please email:  
[Research-findoutmore@rbht.nhs.uk](mailto:Research-findoutmore@rbht.nhs.uk)

# FUNDRAISING EVENTS: GET INVOLVED!



**Alexander Jansons Foundation**  
presents

**2016 Tennis Tournament in aid of Alexander Jansons Foundation**  
Friday 3rd June 2016  
New Place - Parsonage Lane - Parisham Royal - Bucks GL2 3PD  
A 2 course lunch will be served at 1pm at Mary Casey's House

Starts promptly at 9.30 on your designated courts in the Chalfont area. There will be 4 players per court in a changing doubles format. Each doubles team will play between 8 & 8 matches on their allocated court. But we can request further on the format on the day.

We request a CSR donation to enter this tournament which will include the tournament and lunch. Please pay via our Just Giving site <https://www.justgiving.com/alexandersonline>

**Alexander Jansons Foundation**

## 5 A SIDE FOOTBALL

**Date: 4 June 2016**



**AJF Charity Netball Tournament**

**Date: 11 June 2016 10am**



**JOHN HAMPDEN  
GRAMMAR SCHOOL**

**Date: 2 July 2016**

**Details:** Join us at the John Hampden Legacy Tournament Event 2016! For further information please contact Patricia on 01494 679971 or email

[charity@alexanderjansonsfoundation.org](mailto:charity@alexanderjansonsfoundation.org).



**Date: 10 June 2016**

**Details:** Come and join us for a charity shoot in aid of the Foundation. There are 4 stands and 12 shots per stand per person. This will be followed by a 2 course lunch and prize giving. Total cost for the day is £150.



**Annual Jansons Property Rowing Event**  
In aid of the Alexander Jansons Foundation

**Thursday 23th June 2016, 1pm to 8pm**  
at Eton Dorney Rowing Lake, home of the Olympics

Teams: 7 people per team. Team uniforms encouraged, not fancy dress.  
Cost: £360 per boat (8 rowers and 1 cox). If anyone would like to get sponsoring and donate more, AJF Foundation will be very grateful. Includes BBQ for rowers. There will be a pay bar.  
Cheques to: Alexander Jansons Foundation, please.

Places strictly limited, first come first served. Open to both men, ladies or mixed teams. If you would like to enter but don't have enough people to make a team, let us know and we'll try and fit you into a scratch team.  
Spectators are welcome, and for an additional cost you can also enjoy the BBQ too.

**jansons** **Alexander Jansons Foundation**

[www.jansonsproperty.com](http://www.jansonsproperty.com) | [www.alexanderjansonsfoundation.org](http://www.alexanderjansonsfoundation.org)



**Date: 26 June 2016**



**Date: Friday 22 July to  
Saturday 23 July 2016**

**London to Windsor cycle ride**

**Date: Sunday 4 September  
2016**



For more information please visit:  
<http://alexanderjansonsfoundation.org/events/> or contact:  
[charity@alexanderjansonsfoundation.org](mailto:charity@alexanderjansonsfoundation.org)



Well done Sanjay for running the London marathon on behalf of AJF. He raised an outstanding amount of £5203!