



# **The ICC Service**

The South Yorkshire Regional  
Inherited Cardiac Conditions Service

Pete Reynolds, 27

Adam Green, 18

Matthew Dewhirst, 17

Scott Rennie, 25

Robert Poysor, 15

Leanne Haddrell, 21



**12** young sudden deaths a week  
and every loss is heartbreak

**C**ardiac  
**R**isk in the  
**Y**oung  
[www.c-r-y.org.uk](http://www.c-r-y.org.uk)



Matthew Bailey, 14

Jack Phillips, 14

Scott Jackson, 32

Howard Jennings, 33

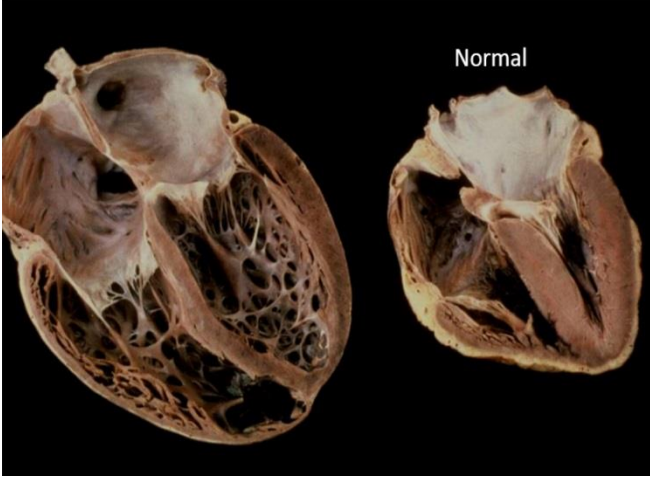
Alexander Edwards, 12

Ashley Goodwin, 35

Hypertrophic Cardiomyopathy



Dilated Cardiomyopathy

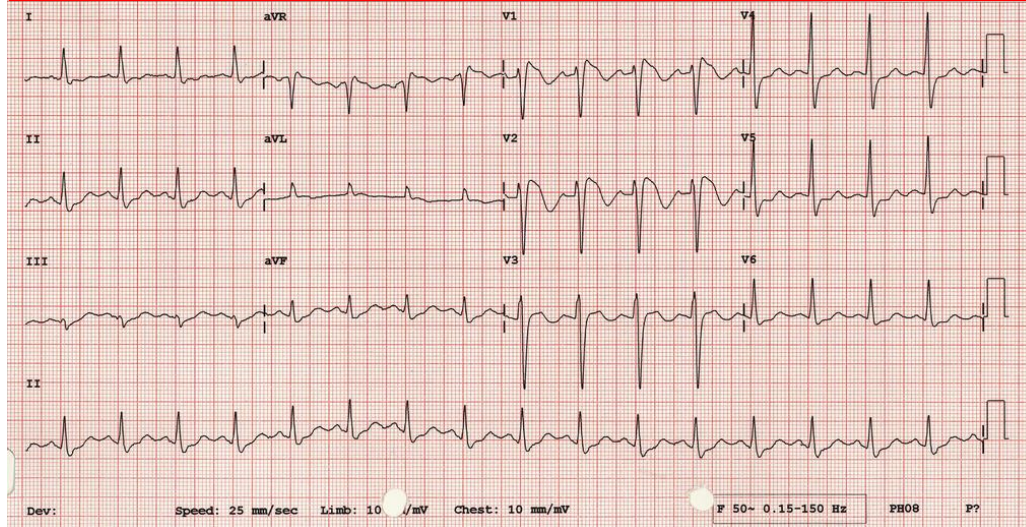


Structural

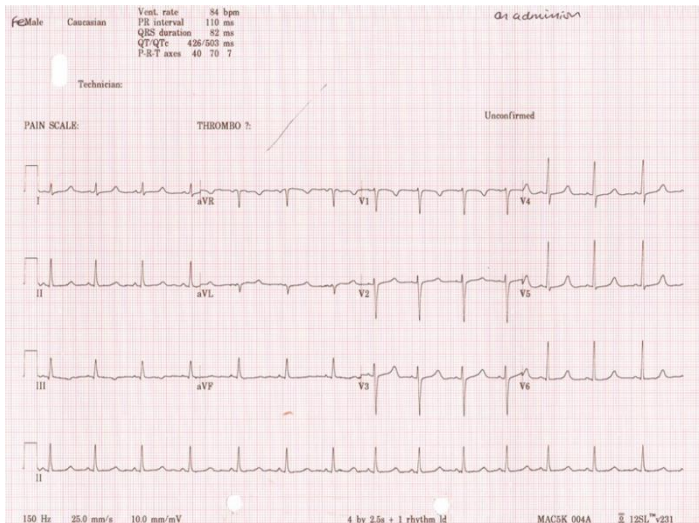




# Brugada



# Non Structural



LQT



CPVT

## Aortopathies

- Familial Aortic Dilatation/dissection
- Bicuspid Aortic Valve

## Neuromuscular disorders

- Muscular Dystrophies
- Myotonic Dystrophy
- Friedreich's Ataxia

## Others

### Connective tissue disorders

- Marfan Syndrome
- Ehlers Danlos Syndrome
- Loeys-Dietz Syndrome
- Beals-Hecht Syndrome

**Familial Hypercholesterolaemia**

EP

ICC

ACS

Surgery

Heart Failure





Individual

Family





Extended Family



# Sheffield ICC Service

- Access to specialist diagnostic services
- Familial approach to management
- Initiation of appropriate screening
- Nurse counselling and support
- Patient education and information
- Point of contact
- Access to genetic testing

## ICC Clinic

- 12 clinics / week
- Consultant, Nurse Specialist

## Fabry Clinic

- 6 per year
- Consultant Cardiologist, LSD Consultant, Nurse Specialist

# Clinics

## EDS Clinic

- 6 per year
- Consultant Cardiologist, EDS Consultant, Nurse Specialist, Genetic Counsellor
- One stop clinic with echo & MRI same day

## Outreach Clinics

- Chesterfield
- Weekly
- Barnsley
- Monthly



# Benefits of outreach

- Easier for the patient
- More likely to access the specialist service
- Family are more likely to come forward for screening

BARNESLEY

DONCASTER

SHEFFIELD

ROTHERHAM

# Multi Disciplinary Approach



Specialist  
Imaging

Genetics

Cardiothoracics

Paediatrics

Cardiology



Charities

Clinical  
Genetics

Coroner

Hospital  
Specialists

ICC Nurse  
Specialist

Clinic

Investigations

Patients and  
relatives

Consultants

# Patients and Families

- Access to specific accurate information
- Need answers to questions
- Many anxieties
- Extra support
- Access to key contacts





# Who to refer

Anyone with an ICC

- Discuss screening
- Refer for genetic testing

1<sup>st</sup> degree relative of patients with an ICC



**Any Questions?**