



# Developing a pathway for the management of patients and families with potential inherited cardiac conditions within a district general hospital.

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BCUHB (East)

# The problem nationally



# Arrhythmia nurse co-ordinators



**AFA**  
atrialfibrillationassociation  
www.atrialfibrillation.org.uk

**Feel the pulse to beat the stroke!**

- FACT  
Atrial Fibrillation (AF) is the most common heart rhythm disorder
- FACT  
AF is often a silent condition going undetected
- FACT  
Atrial Fibrillation causes an irregular pulse
- FACT  
An irregular pulse can cause small blood clots to form making stroke more likely
- FACT  
1 in 4 stroke victims have Atrial Fibrillation

**Feel Your Pulse**  
The best way to detect AF

BEATING HEART DISEASE TOGETHER

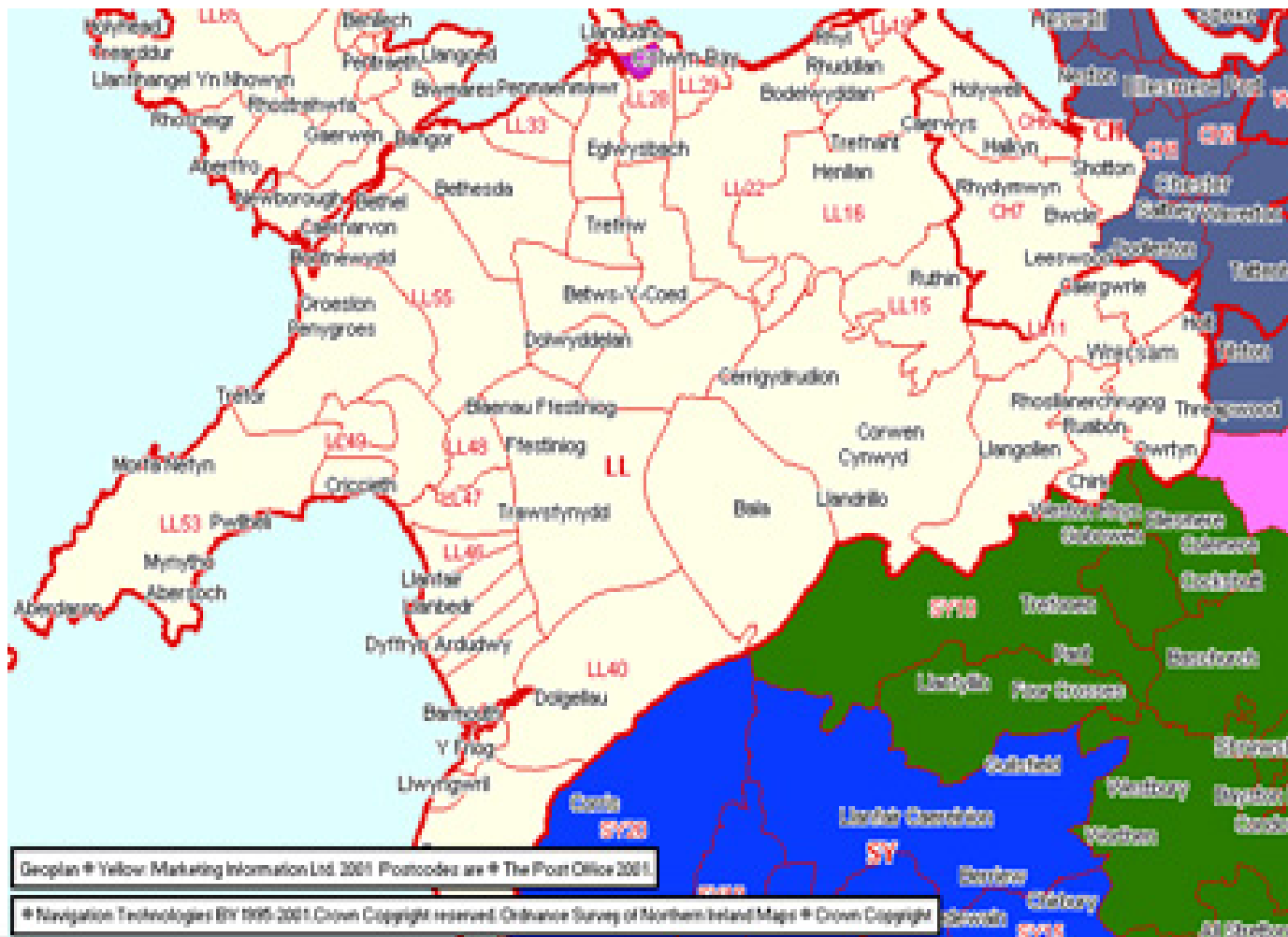
bhf.org.uk



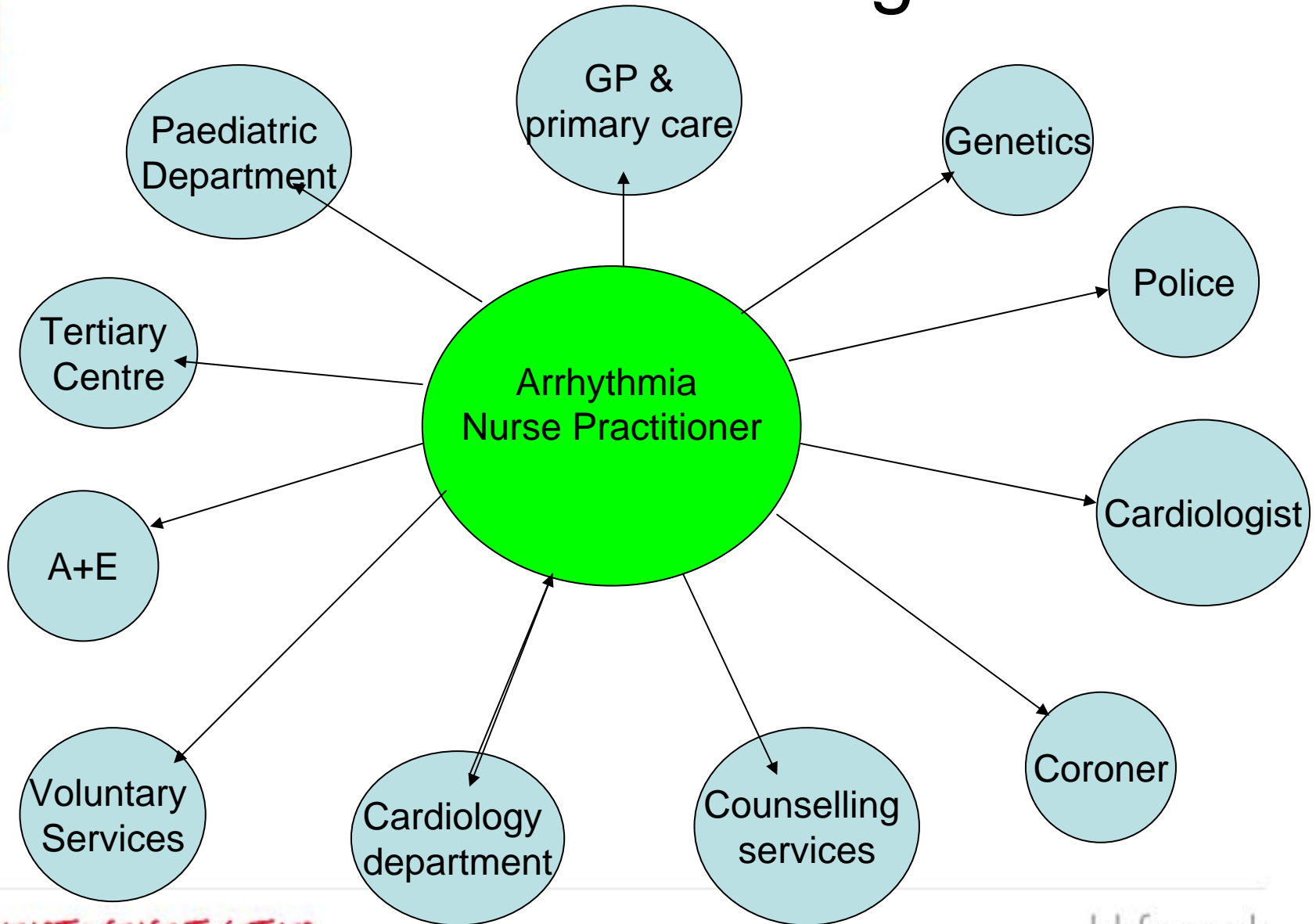
British Heart Foundation

CYMRU

# ...so the problem locally



# ....where do we begin?



Here is Edward Bear,  
coming downstairs now,  
bump, bump, bump, on the  
back of his head, behind  
Christopher Robin.

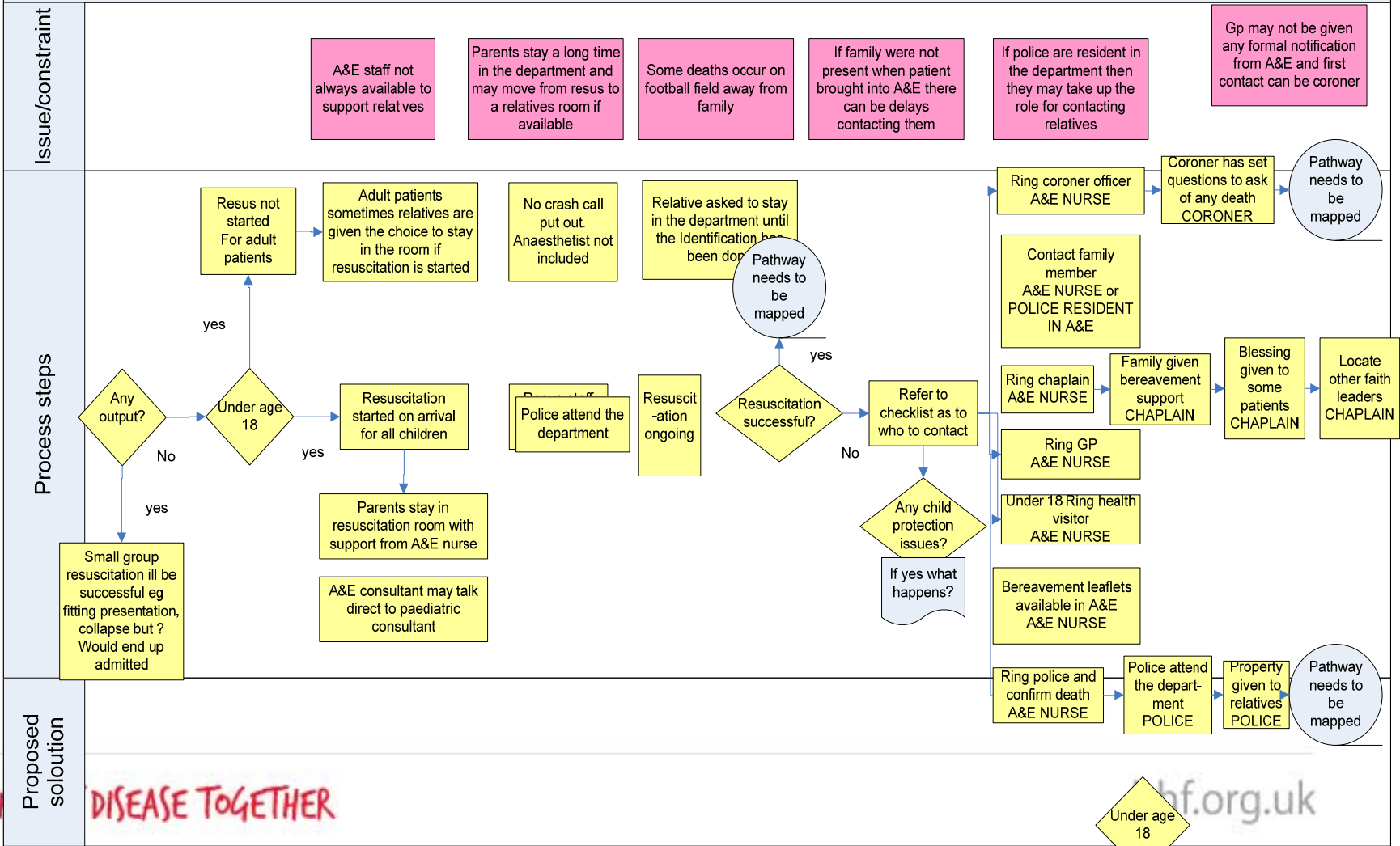
It is, as far as he knows,  
the only way of coming  
downstairs, but sometimes  
he feels that there really  
is another way, if only he  
could stop bumping for a  
moment and think of it.



# Process Map

## Sudden Cardiac Death Process Map

Start – child can not be woken and parent phones ambulance control, End: relatives access genetic service





# Action Plan.

## Sudden Cardiac Death Process Mapping-Action Plan

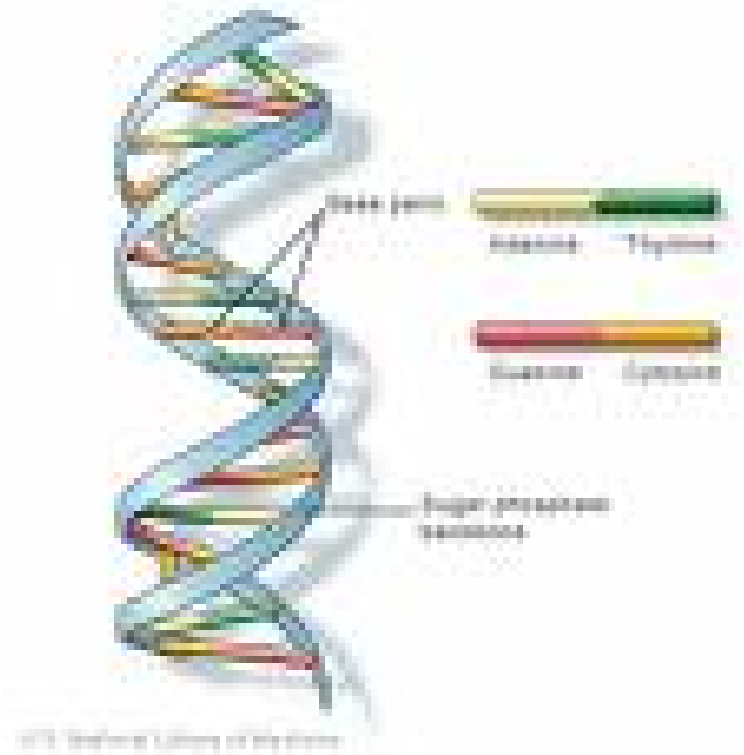
### Statement of intent:-

To develop a service and a referral pathway for patients and families who are at risk from sudden cardiac death. The patients and families who use this service will be affected or have a family member who is affected with a genetically inherited cardiac rhythm disorder.

NEGOTIATED OUTCOMES	RESOURCES	ACTION STRATEGY	TIME SCALE	EVIDENCE
<p><b>1. Summarise the proceedings of the SCD process mapping event (27.09.07)</b></p> <p><b>2. Develop a steering group with key representatives from all areas and arrange regular meetings.</b></p>	<p><b>Time</b> Notes and process map from the event</p> <p><b>Time</b> Co operation of others</p> <p><b>Time</b></p>	<p><b>Arrhythmia nurses to summarise the day and circulate to all members who attended.</b></p> <p><b>Ask all members to comment on summary</b></p> <p><b>Arrhythmia nurses to contact all groups and set a date for 1<sup>st</sup> meeting</b></p>	<p><b>To be completed and circulated by 31 October 2007</b></p> <p><b>14 November 2007</b></p> <p><b>First meeting by 30 November 2007</b></p>	<p><b>Comments received back</b></p> <p><b>Minutes of steering group meeting</b></p>

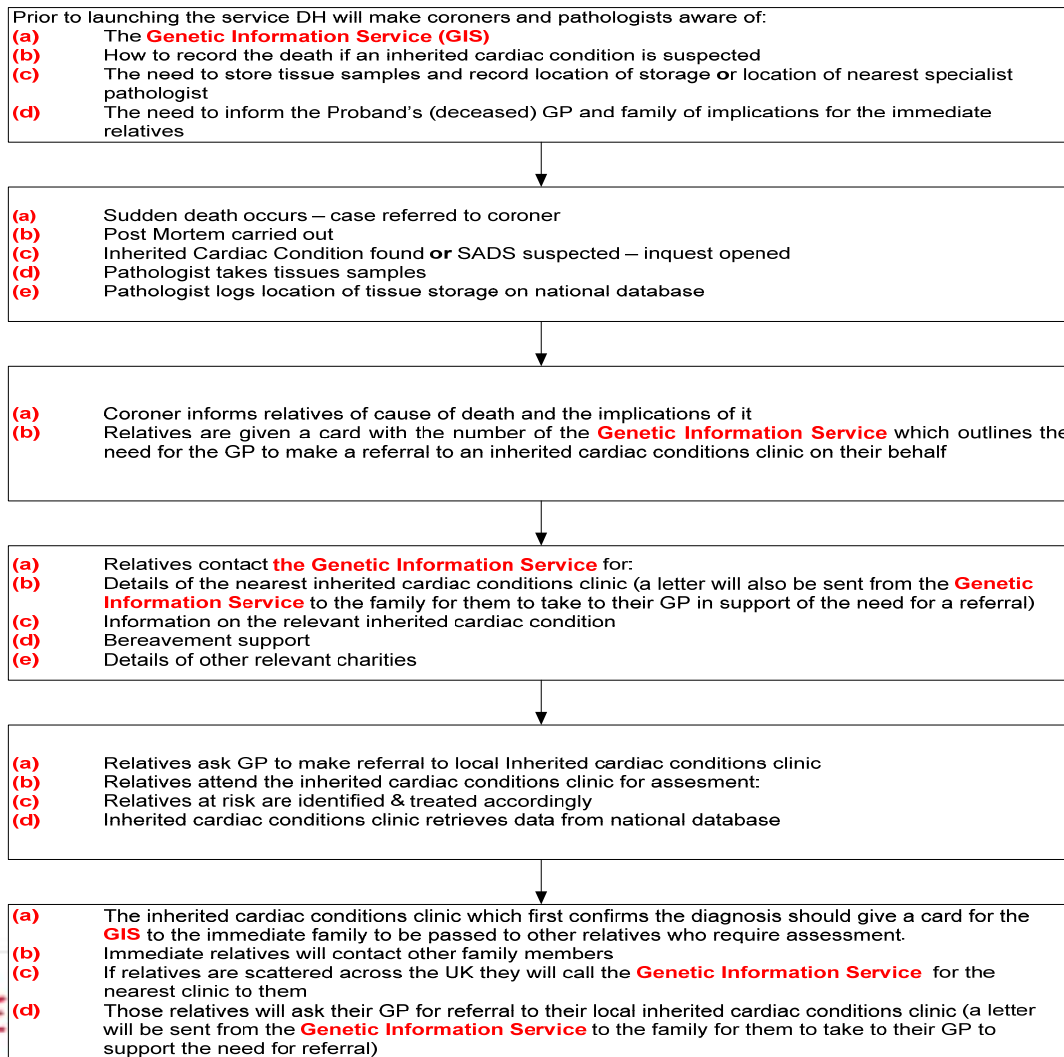
# Gaining Consent and Banking DNA!

- Heart to Heart: Inherited Cardiovascular Conditions Services.
- Chapter 7.  
Recommendation 7.9.1  
(A): *Ensure appropriate retention of samples following a sudden cardiac death*



# Genetics Information Service

## BHF Genetic Information Service



**SUD ? 16 ? 18 – 40 years**

**Coroner informed/ coroners officers to ask family if they fit criteria**

**No**

Normal policy following sudden death

**Yes**

Coroner informed / Consent -samples taken (ie spleen / liver / blood)As per trust policy

Arrhythmia nurses informed

Genetics dept informed

Cardiologist/paediatrician informed

Contact made with NOK

- FH
- Genetic counselling
- Consent for storage of DNA
- Ongoing support

- Cardiology Assessment
- ECG, ECHO
- Provocation testing

**1<sup>st</sup> degree Relatives identified**

Letter inviting relatives for referral via GP

Inherited cardiac condition confirmed

Relative referred

**No**

Continued follow up ? For how long

**Yes**

Medical Management

Results of genetics test or diagnostic test if symptomatic

Gene mutation Identified

No mutation

Negative

Positive

- FH Negative
- Molecular genetic test negative
- Cardia assessment

Discharge

Continued FU Counselling

Discharge if all above criteria negative



# Genetics Information Service

- Inherited Cardiac condition found or SADS suspected – inquest
- Pathologist takes tissue samples
- Pathologists logs location of tissues storage on National data base.
- The need to inform the probands GP and family of implications for the immediate relatives.

# Audit



# Summary

- New working partnerships have been developed
- Increased referrals to genetics department
- Better communication across disciplines.
- Arrhythmia's nurses across North Wales are trying to standardise practice.
- Increased awareness for other healthcare professionals and non healthcare professionals
- New established links with local/national voluntary groups.
- Our service compliments the GIS
- **We are meeting the needs of patients and families!**



Thank You

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Any Questions