

# **ADULT CONGENITAL HEART DISEASE AN OVERVIEW**

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2018

# AIMS OF THIS TALK

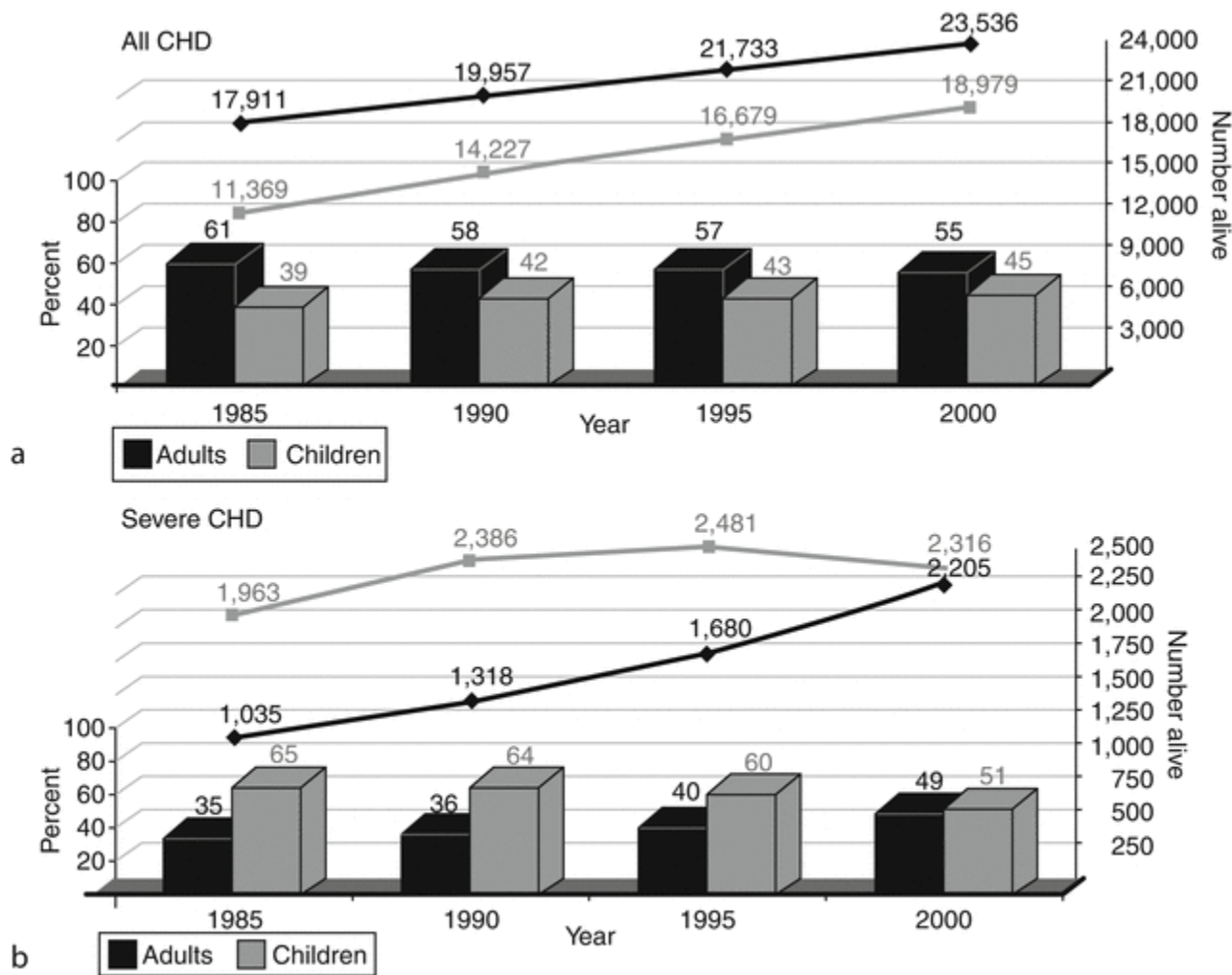
- Develop knowledge and skills.
- Develop insight into on-going needs of the patient group & changes in their condition.
- Develop ability to provide information on services suitable for individual patients and family members.
- Enable patients to participate in decisions regarding health & social issues that arise throughout life.

# OUTLINE

- Set the scene population
- Outline team
- What do we do
- Role of CNS
- Lesions
- Physical and psychological issues
- Guidelines

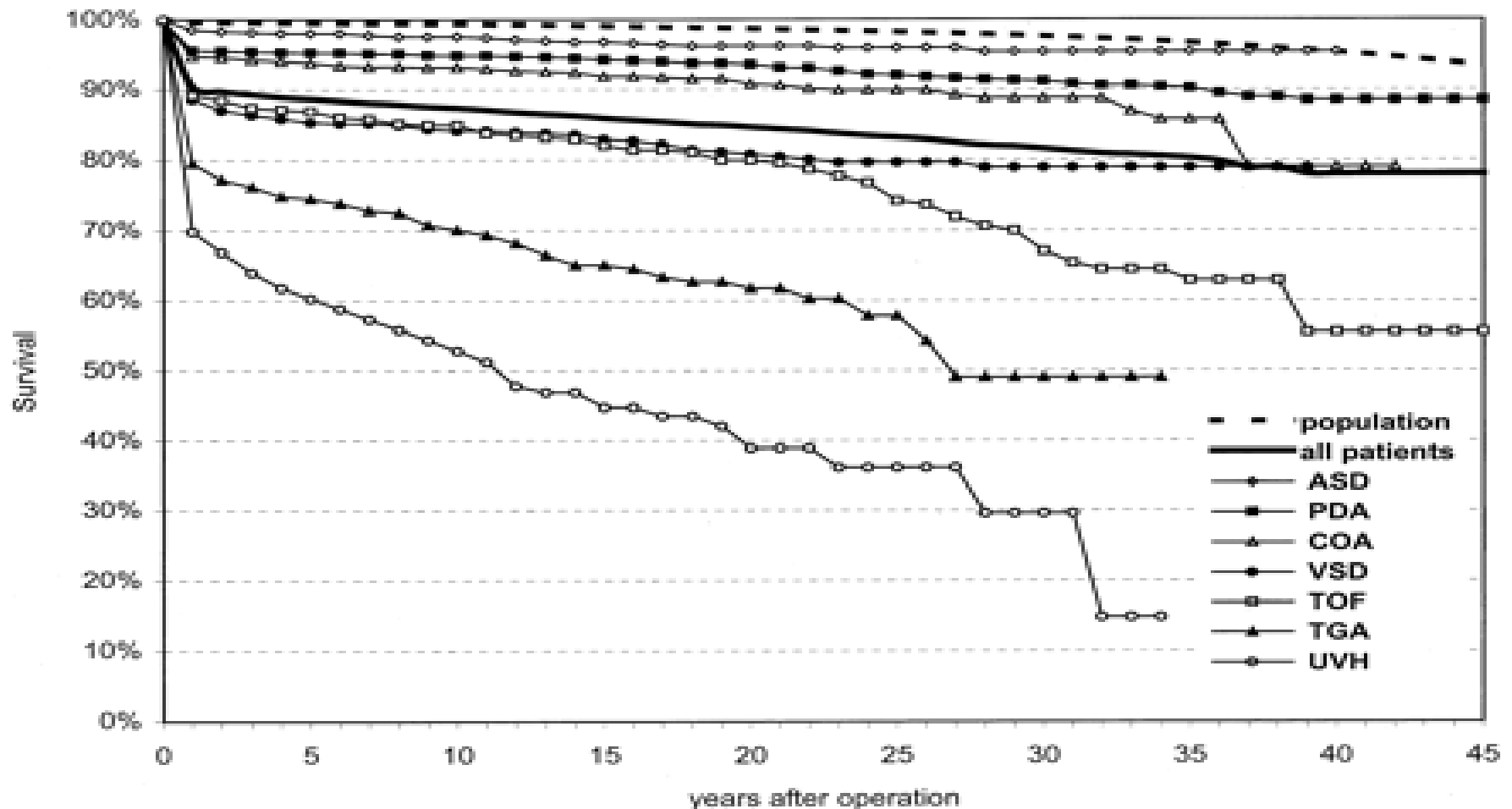
# POPULATION

- Incidence: 8 per 1000 live births.
- 40 yrs. ago mortality from untreated CHD was 60%- 70% over the age of 18 years.
- Success of cardiac surgery and cardiology in infancy improved life expectancy.
- 85% of CHD patients, including complex, rare and severe conditions will reach adulthood.
- **More** adults than children with CHD.
- Average life expectancy 49 years



*Numbers and proportion of adults and children with all CHD (a) and severe CHD (b) in 1985, 1990, and 2000 (From Marelli et al. (2007) J Am Coll Card)*

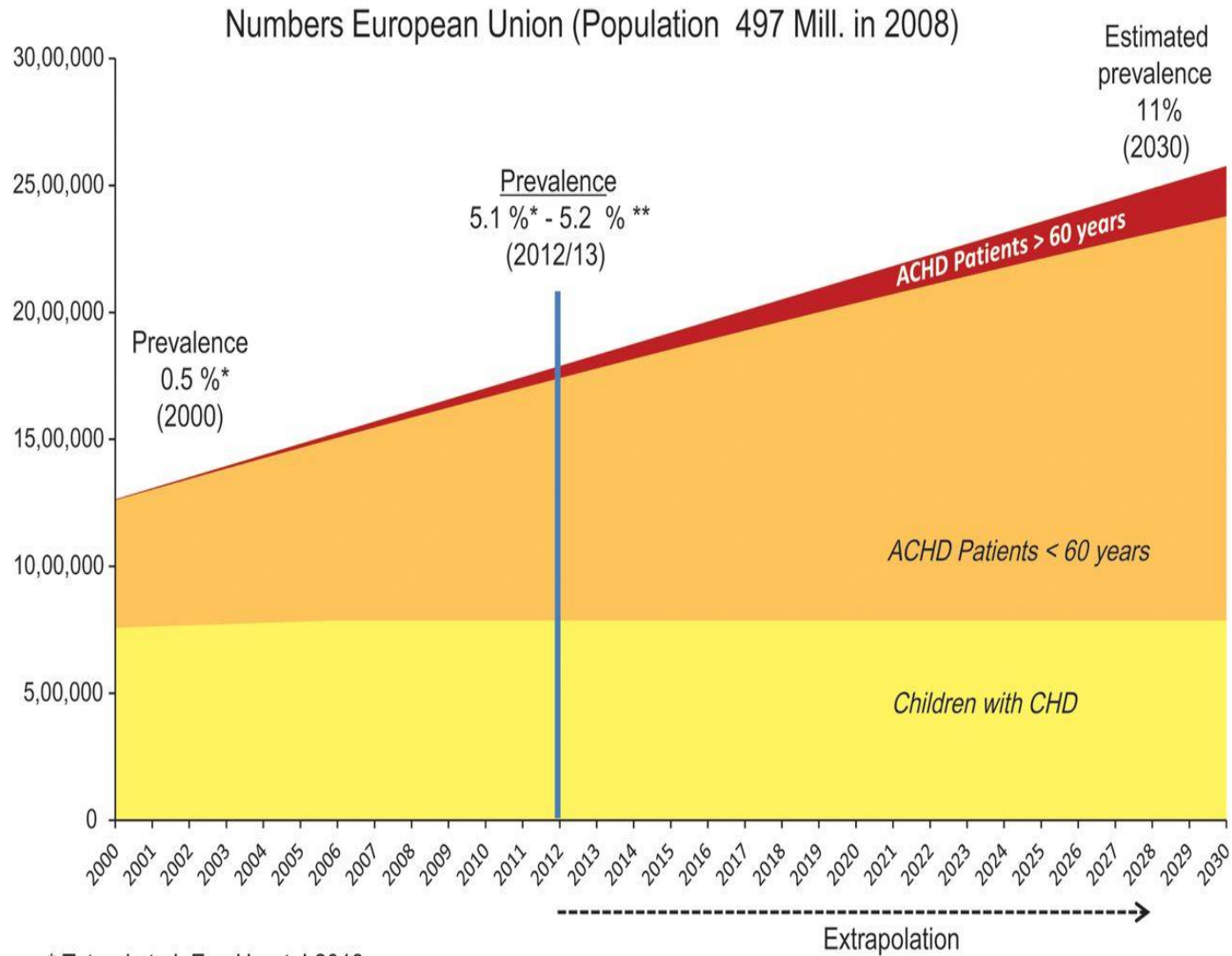
## Nieminen et al, Circulation 2001



# Relative age

	Patient's age (years)										Age difference:	
	20	25	30	35	40	45	50	55	60			
ASD	25	26	32	38	42	47	52	57	61	<div></div>	>40	
Valvar disease	29	31	36	40	45	49	54	59	63	<div></div>	30-40	
VSD	28	30	36	40	44	49	53	59	63	<div></div>	20-30	
Aortic Coarctation	32	33	38	43	47	52	56	62	66	<div></div>	10-20	
AVSD	33	34	39	44	48	52	57	62	66	<div></div>	5-10	
Marfan syndrome	37	38	42	46	50	54	59	64	68	<div></div>	2-5	
Tetralogy of Fallot	37	38	42	47	50	54	60	65	69	<div></div>	<2	
Ebstein anomaly	42	43	47	51	54	59	63	68	72			
Systemic RV	46	48	51	55	59	63	67	72	76			
Eisenmenger syndrome	57	58	62	65	69	73	77	81	84			
Complex CHD	58	59	63	67	70	74	78	82	85			
Fontan	64	65	68	72	75	78	82	86	91			

Values present relative age adjusted for predicted 5-years mortality. Colors reflect the difference between relative and actual age. For example a 40 year old Fontan patient has a mortality rate that is comparable to that of a 75 year old individual without CHD.

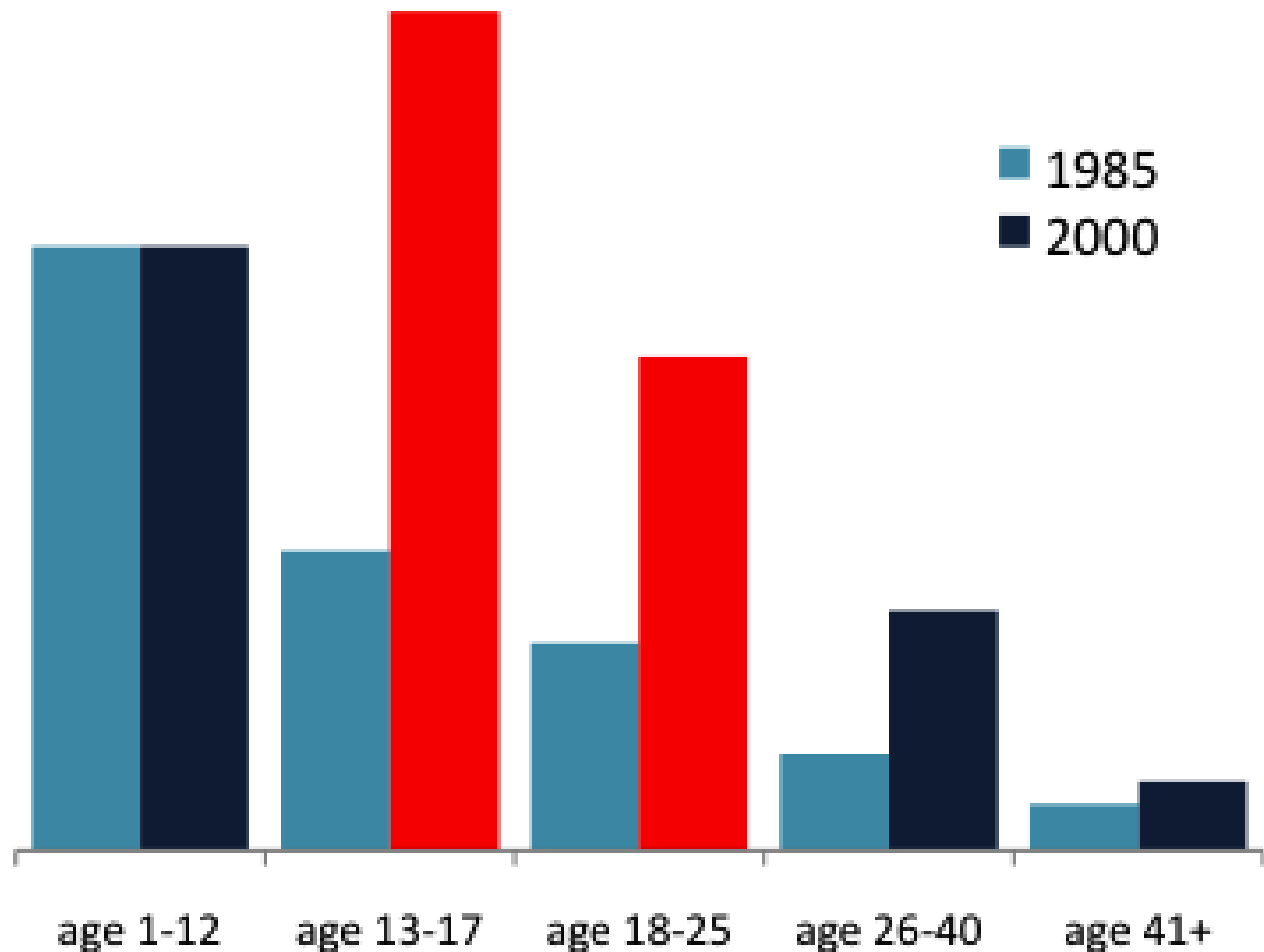


\* Tutarel et al. Eur. Heart J 2013

\*\* German Competence Network for Congenital Heart Disease (data on file)



number of 13-25 year olds **increased x 3**



# CURRENT POPULATION

- 8,000 **Adults** South West
- 6,500 **Children** 135,000 adults and young people England
- In 2000 equal numbers of those alive with severe CHD were adults.



# WHO KNOWS?!

*Grown-up Congenital Hearts  
(GUCH)*

*Adult Congenital Heart  
Disease (ACHD)*

# BRISTOL HEART INSTITUTE



# OUTPATIENTS





# ADULT CONGENITAL TEAM

- BHI Cardiologists x 5, Surgeons x 3
- Specialist registrar, registrar x 2
- CNS x 3
- Obstetric team, 108 new pts
- Consultant Radiologists
- Anaesthetist
- Peripheral clinics in 7 D.G.H's
- Barnstable, Cheltenham, Swindon, Taunton, Exeter, Torbay, Truro

# WHAT DO NURSES DO?

- In-patient and out patient issues
- Pre-assessment clinics
- Surgery, cardiology, medical admissions, arrhythmias, endocarditis, heart failure
- Learning disability work
- Pregnancy/contraception
- Teenage and young adult clinic
- End of life care
- Pulmonary hypertension
- Telephone Advice >2000 calls pa
- Write patient information
- Education to pts and staff

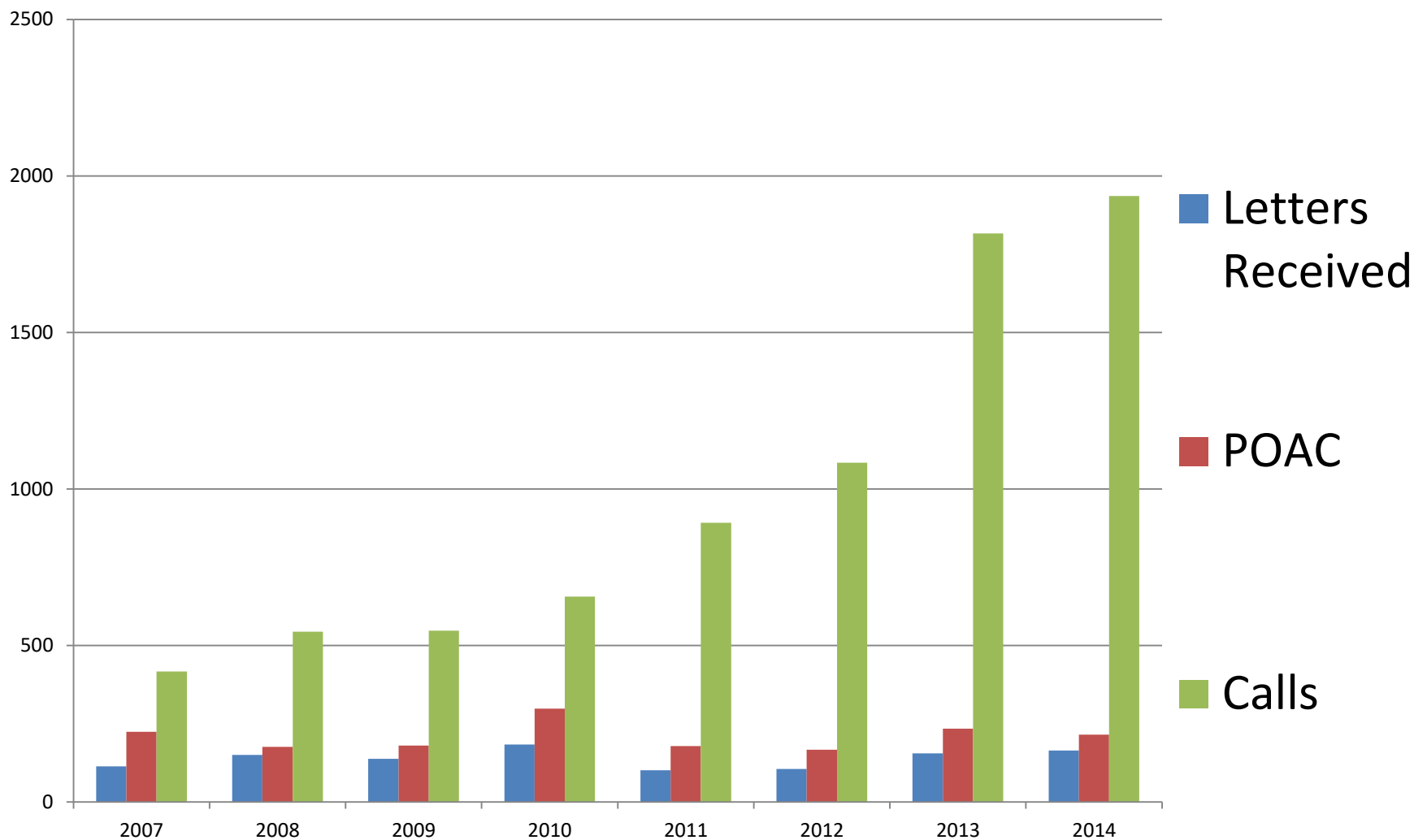




# ADVICE LINE



# 2007-2014



# COMMON CONGENITAL HEART DEFECTS

• Atrial Septal Defect	10%
• Ventricular Septal Defect	30%
• Tetralogy of Fallots	6%
• Transposition of the Great Arteries	4%
• Coarctation of the Aorta	7%
• Patent Ductus Arteriosus	10%
• Aortic Stenosis	6%
• Pulmonary Stenosis	7%
• Other	<b>20%</b>

# PREDISPOSING FACTORS

- Maternal drugs e.g. anti-epileptics, lithium, alcohol
- Chromosomal Aberrations e.g. 1 in 700 Down's Syndrome. 40% D.S. have C.H.D. Turners/Williams Syndrome
- Environmental Factors e.g. Radiation
- Infection/Virus e.g. Rubella
- Maternal Conditions
- e.g. Diabetes



# MARFANS SYNDROME

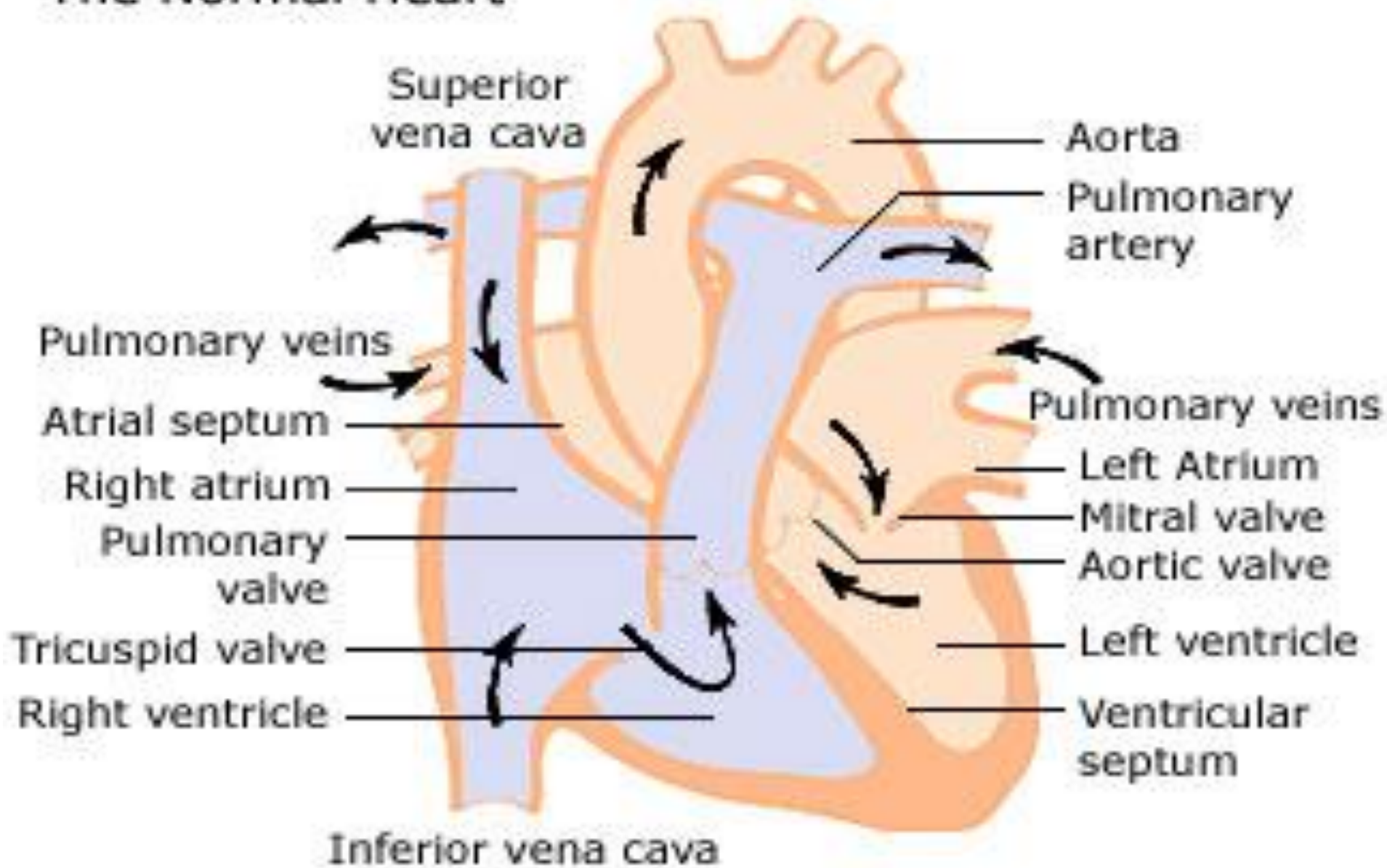
- Connective tissue disorder, the heart (aortic dissection), eyes (dislocated lenses) and skeleton (scoliosis)
- Affects 1 in 5,000 births
- Reduced life expectancy in many patients
- **Cardiac manifestations** such as aortic dissection, aortic regurgitation and heart failure
- Cardiac surgery for abnormalities of the aorta
- Beta blockers
- *[www.marfan.org.uk](http://www.marfan.org.uk)*

# MARFANS SYNDROME

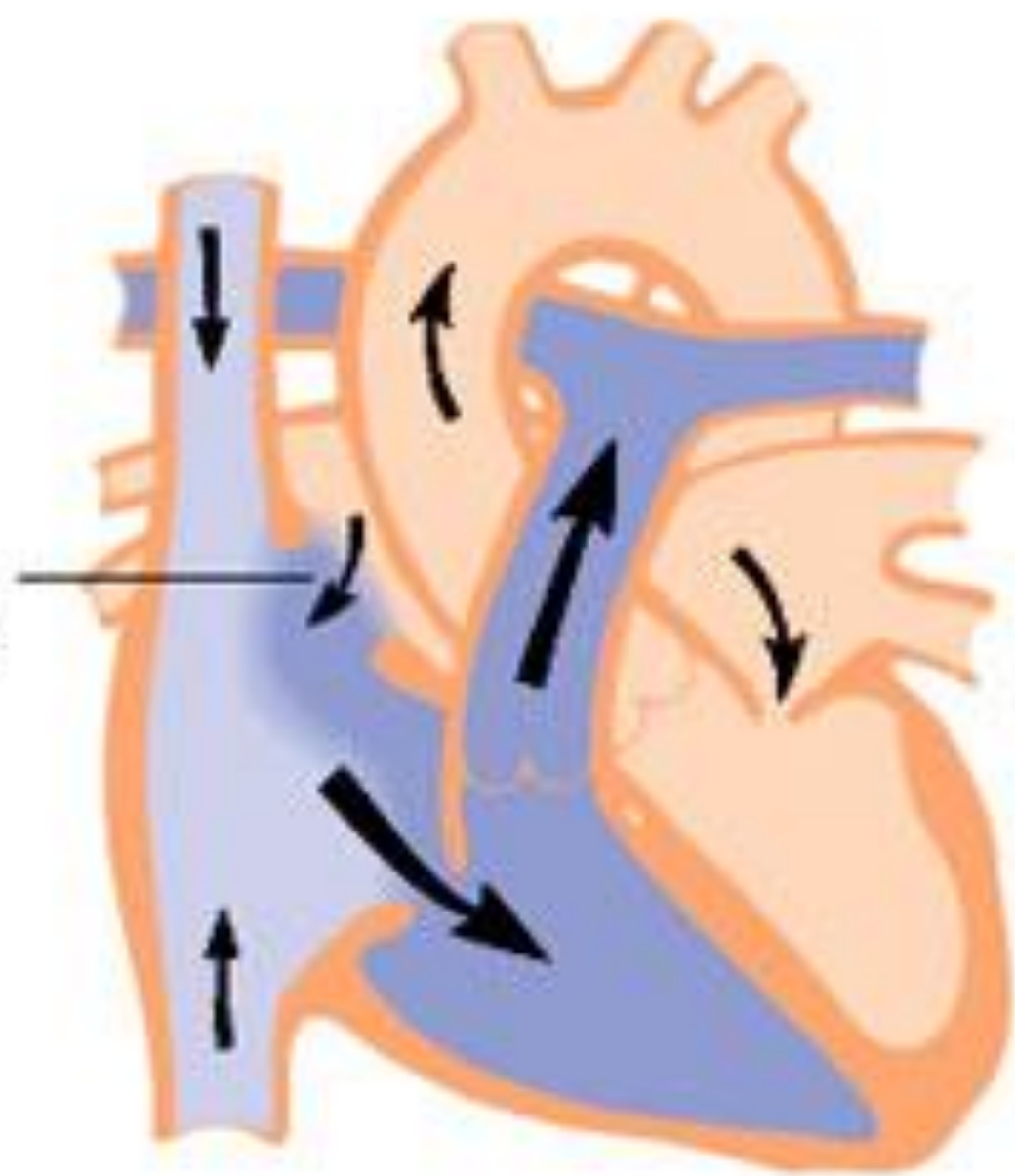
- Tall and slender build.
- Disproportionately long arms, legs and fingers.
- A breastbone that protrudes outward or dips inward.
- A high, arched palate and crowded teeth.
- Heart murmurs.
- Extreme near-sightedness.
- An abnormally curved spine.
- Flat feet.



# The Normal Heart

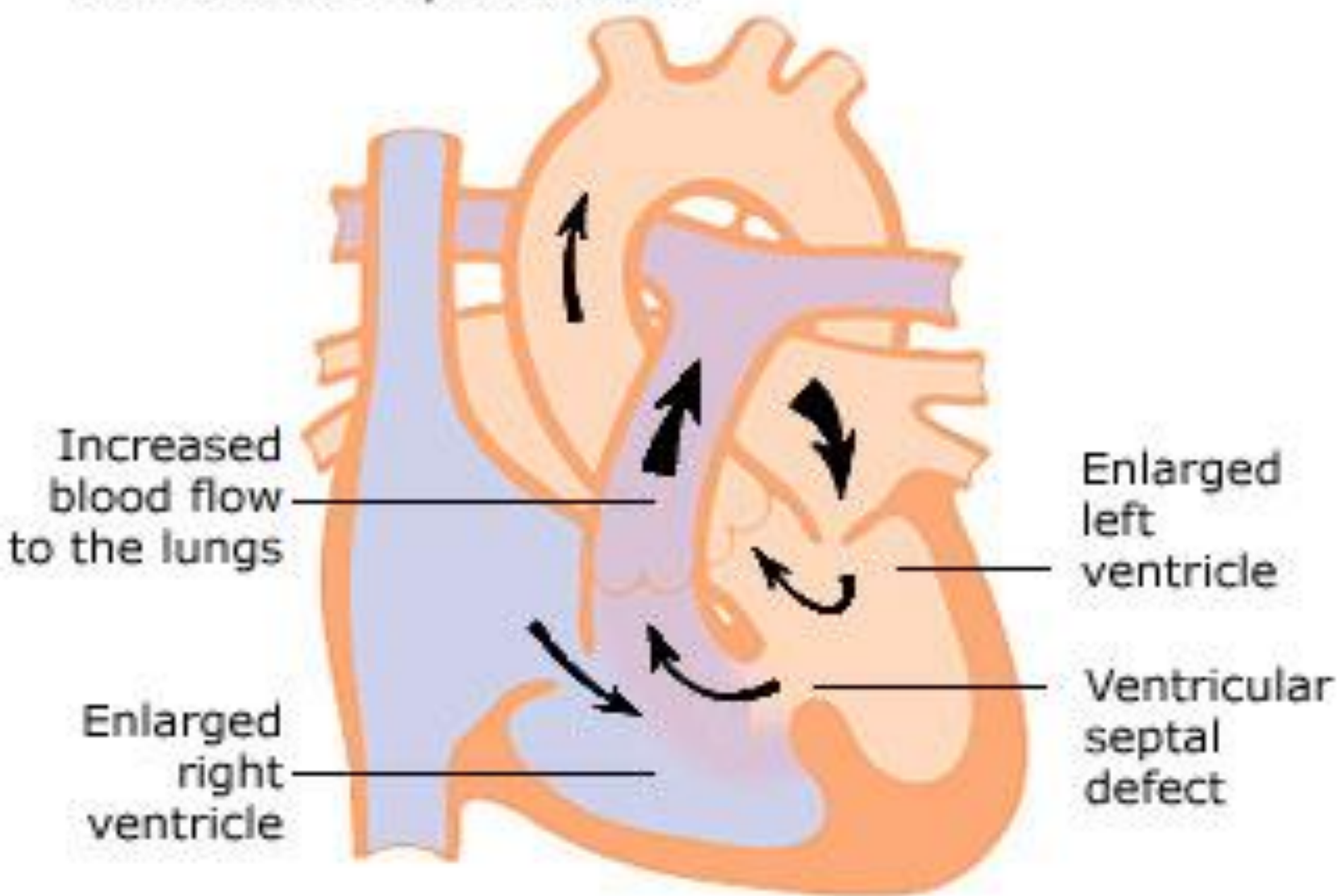


Atrial septal defect

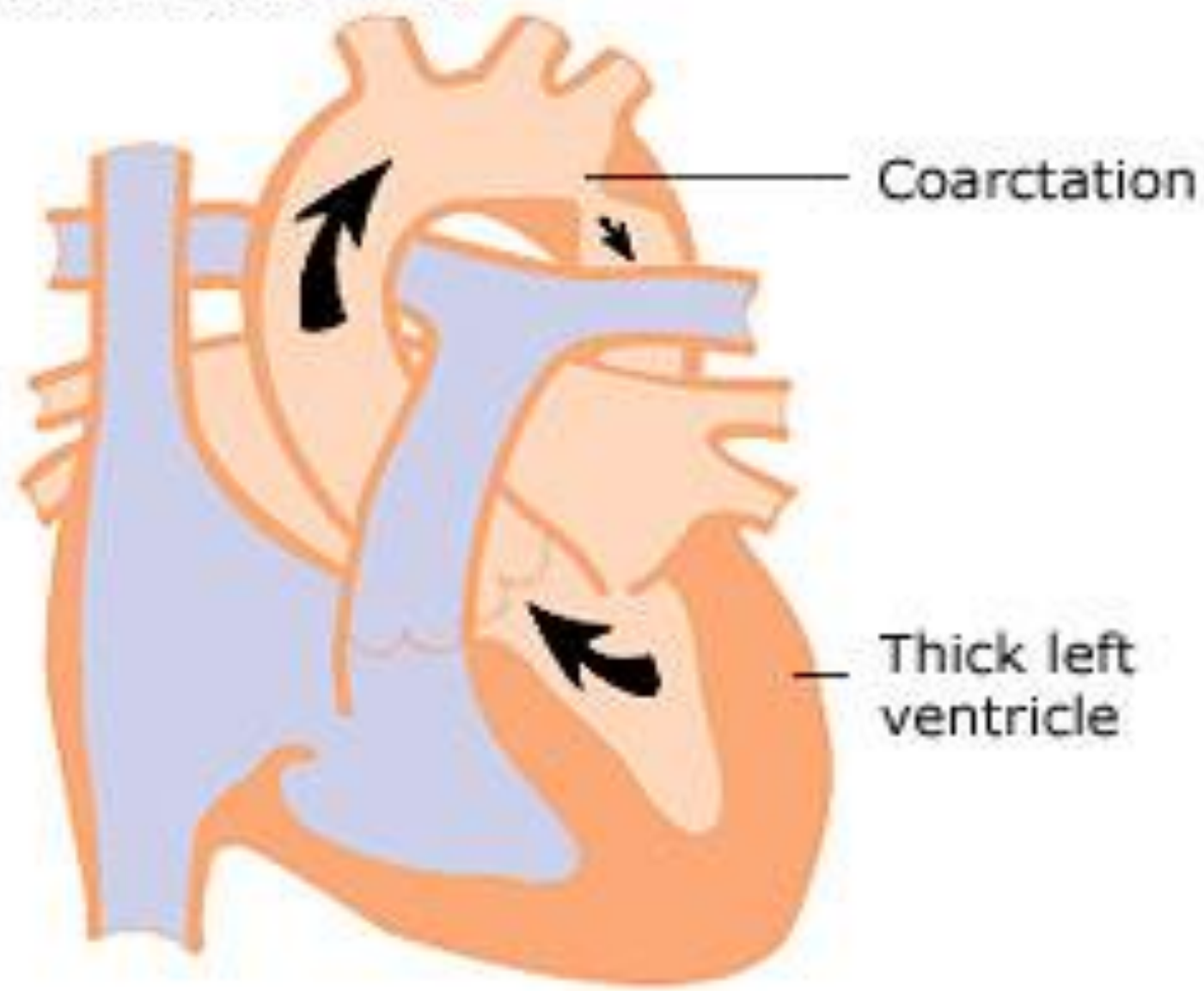




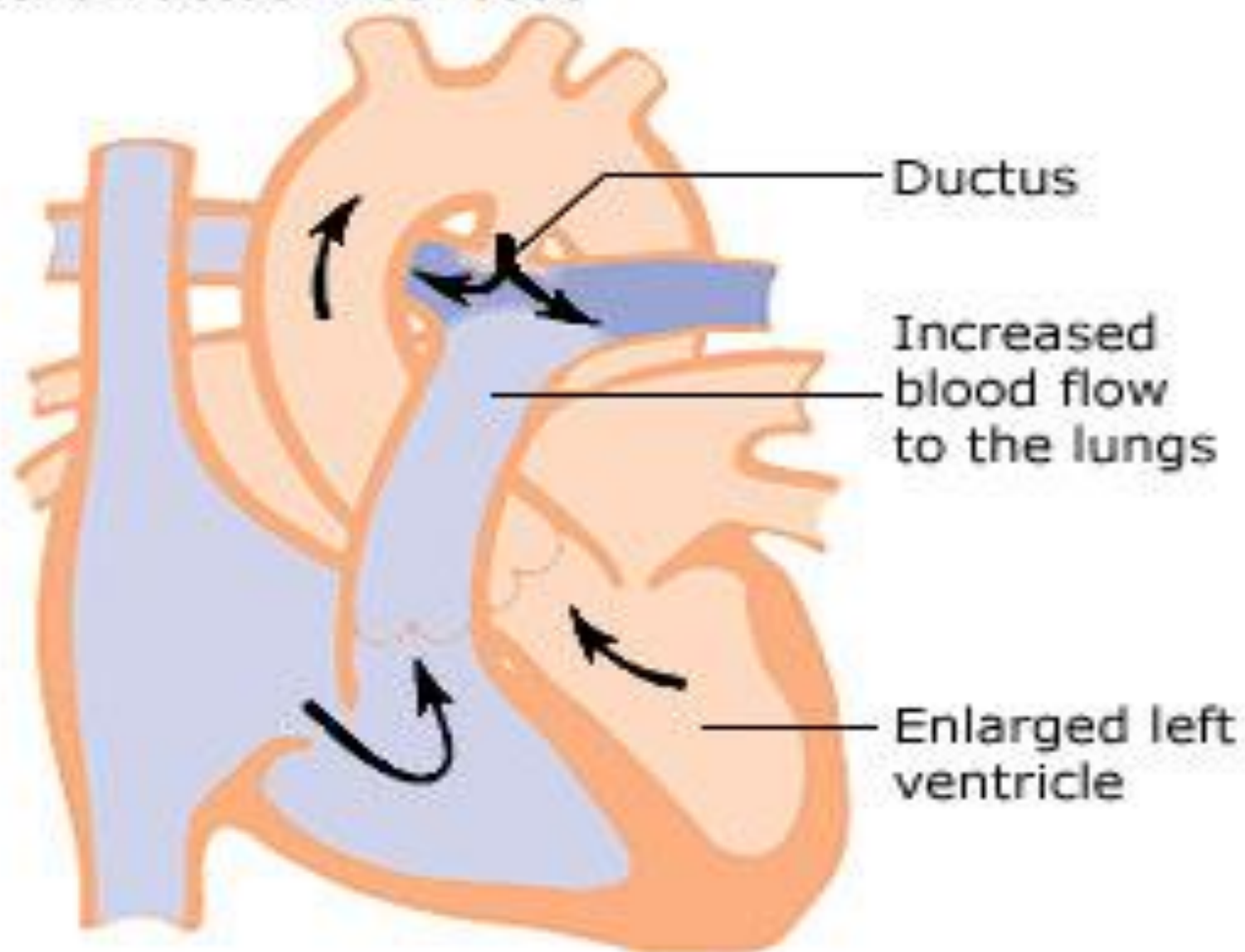
## Ventricular Septal Defect



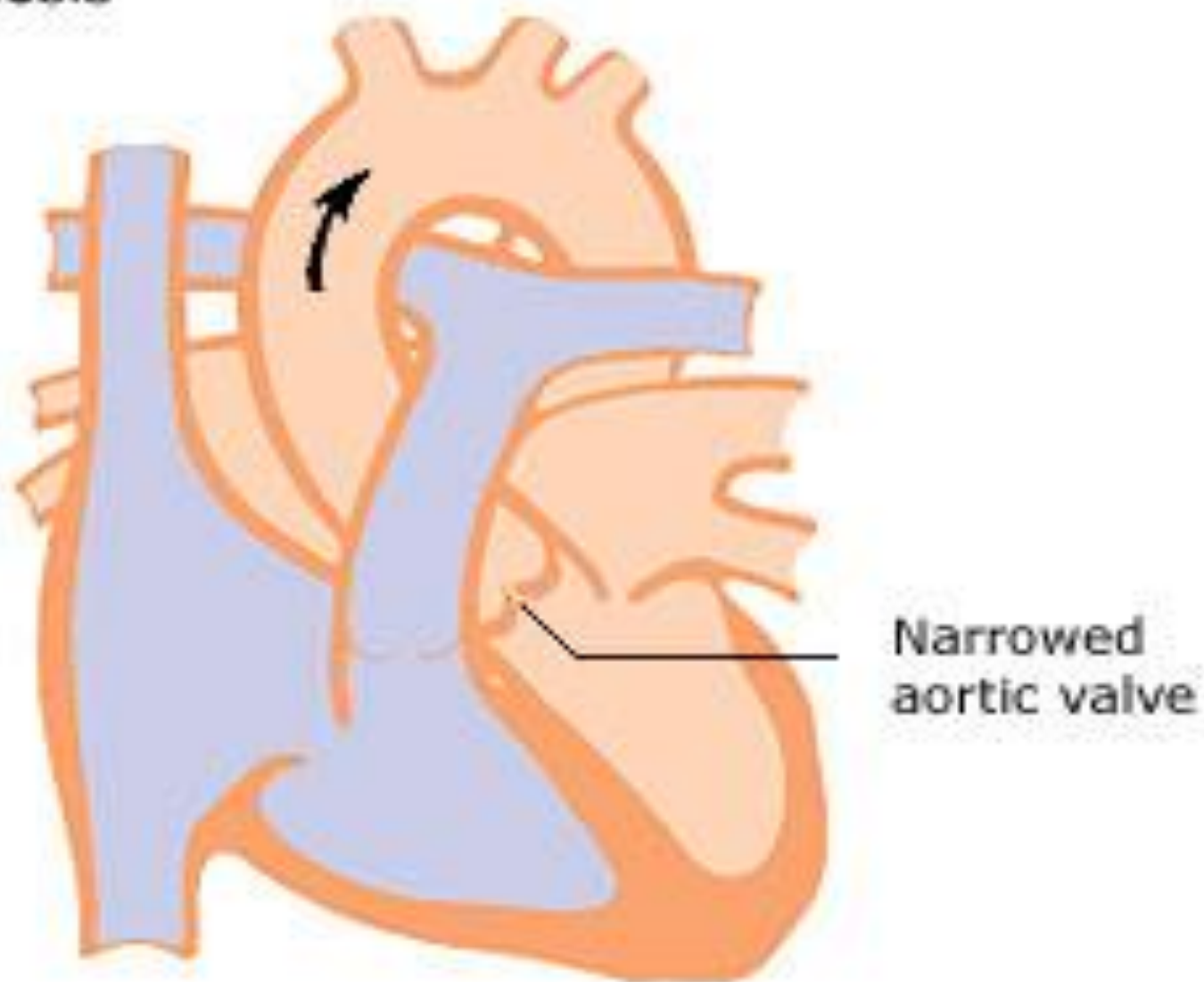
## Coarctation of the Aorta



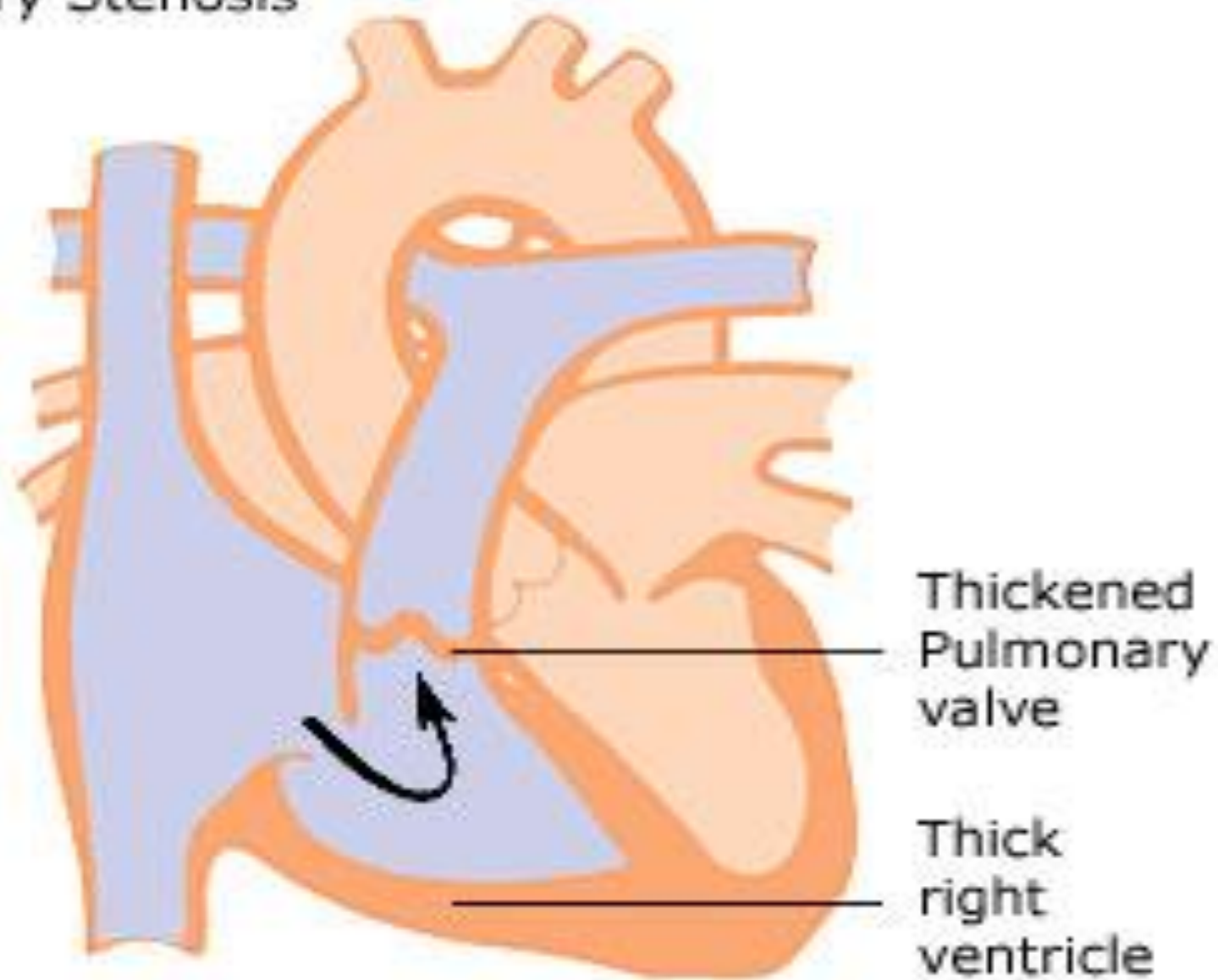
## Persistent Ductus Arteriosus



## Aortic stenosis

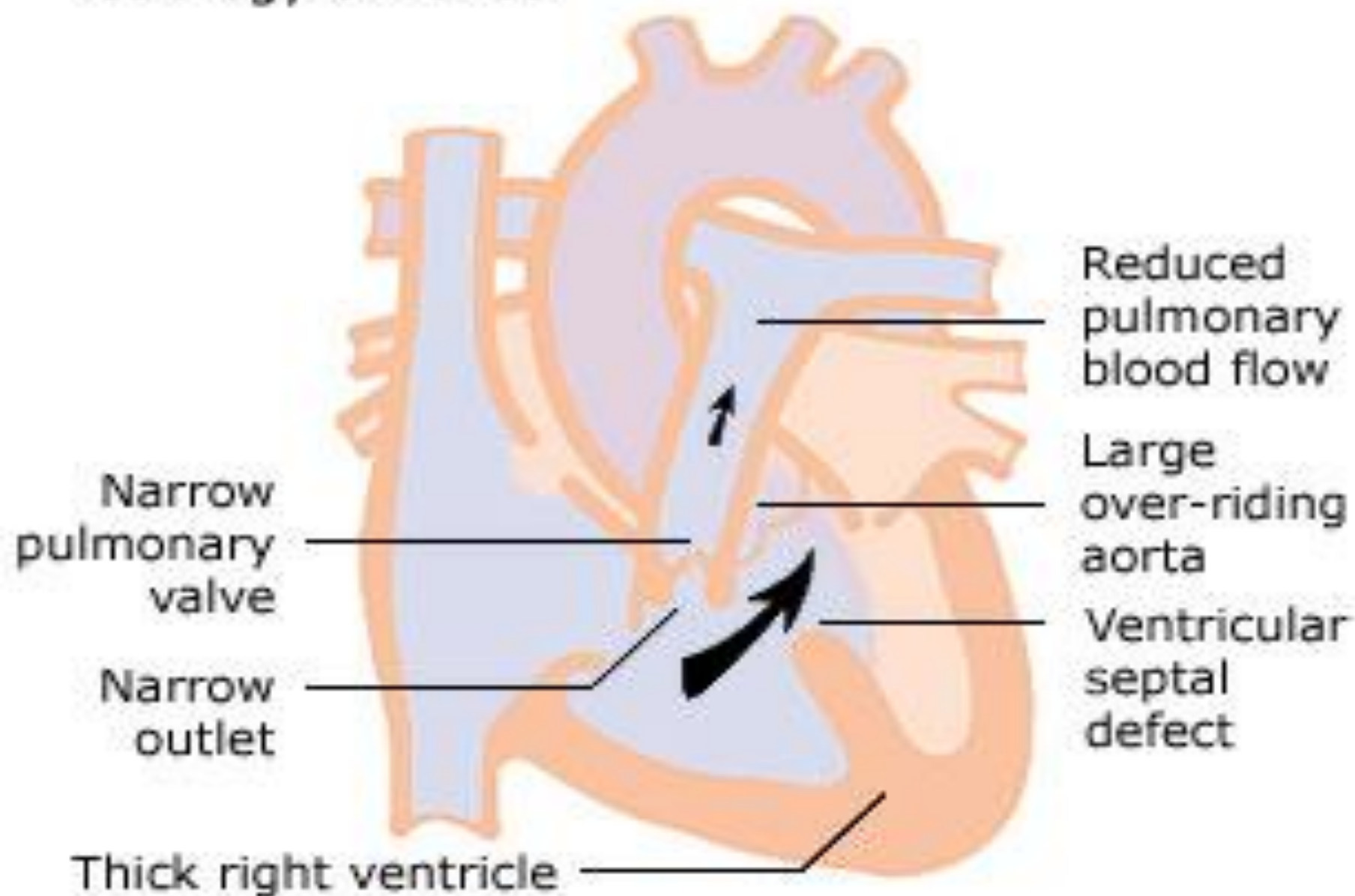


## Pulmonary Stenosis

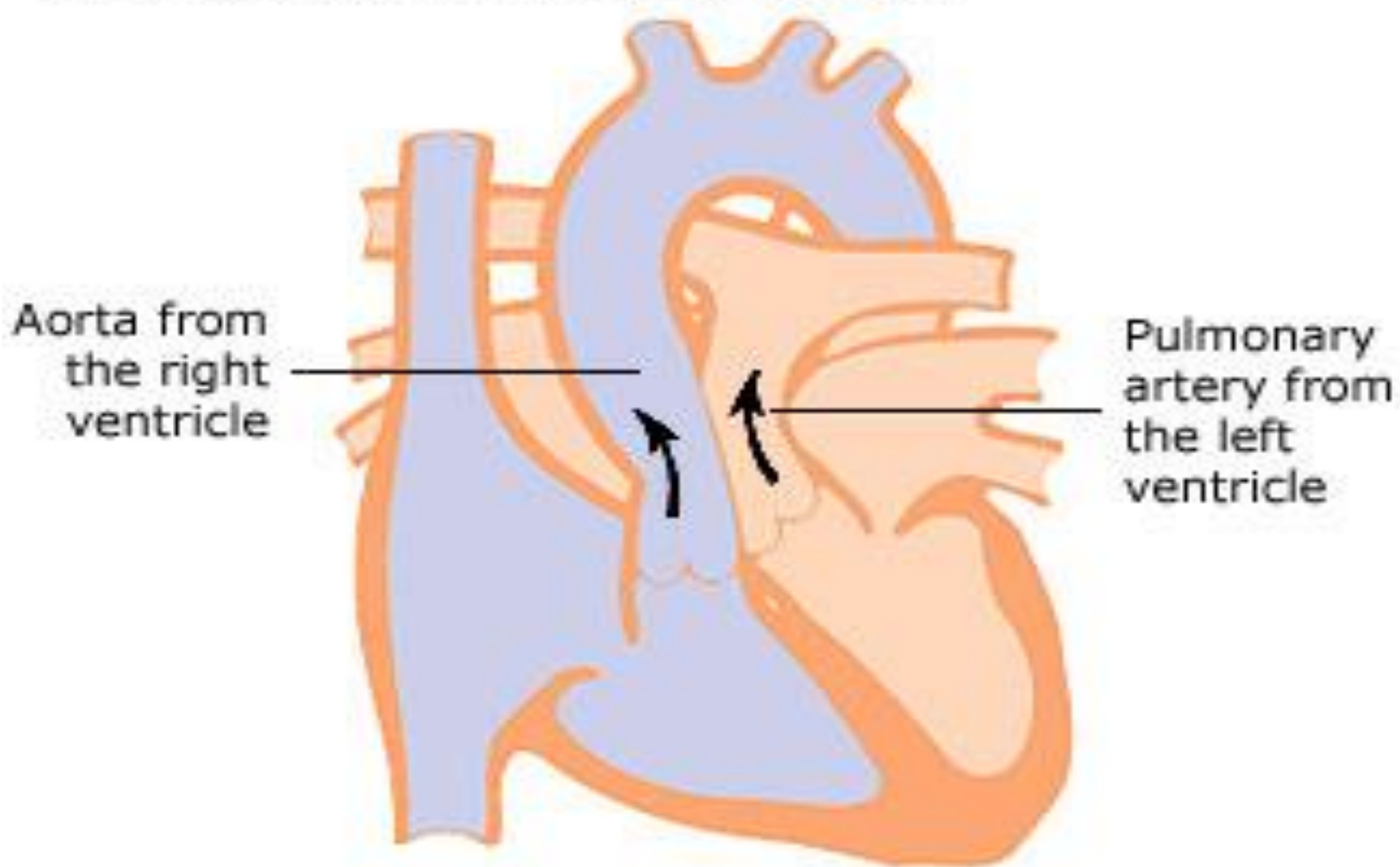




## Tetralogy of Fallot



## Transposition of the Great Arteries



# PHYSICAL ASPECTS OF CARE

- Infective endocarditis.
- Arrhythmias/heart failure.
- Surgery +/- re-operation – risks Intervention.
- Stroke.
- Cyanosis/Polycythaemia.
- Pregnancy/Contraception.
- Coronary Artery Disease.

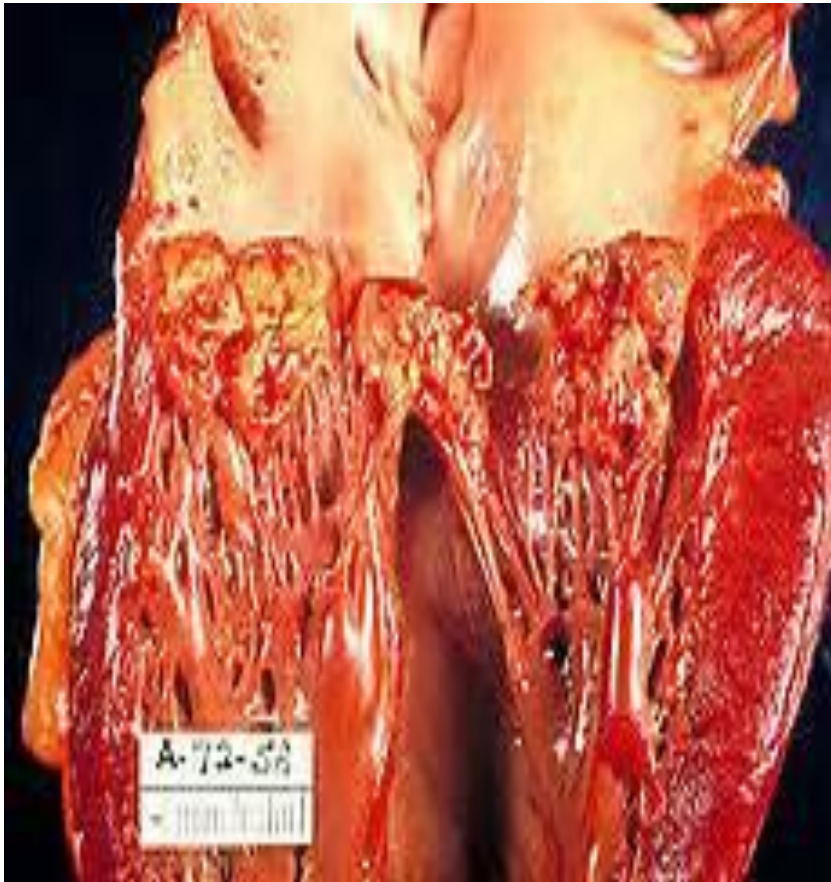


# Piercings



# INFECTION

## ENDOCARDITIS



- Causes/risk
- Diagnosis
- Bloods, TOE, ECG+ CXR
- Urine dip
- Treatment
- Complications
- Prophylaxis
- Nursing

# ARRHYTHMIAS

- Operative procedures from the early years, scarring affecting the conducting pathway.
- A/F, atrial flutter signs of deterioration in patients with Fontans, Fallots, A.S, single ventricle hearts and right sided conduit.
- Treatment return to S/R, anti-coagulate.
- Risk of S.C.D.
- Ablation, pacemaker or I.C.D.
- EOL discussion

# ARRHYTHMIA

- Urgent cardioversion
- Mapping
- Catheter ablation and surgical approaches
- Pacing/ ICD
- Medication/side effects/pregnancy
- **Danger Fontans and Ebsteins ,TGA  
Mustards or Sennings flutter**
- SVT most common
- **VT** in AS + TOF

# RIGHT SIDED ♥ FAILURE

(Cor Pulmonale)

- Fatigue

- ↑ Peripheral Venous Pressure

- Ascites

- Enlarged Liver & Spleen



- May be secondary to chronic pulmonary problems

- Distended Jugular Veins

- Anorexia & Complaints of GI Distress

- Weight Gain

- Dependent Edema



# HEART FAILURE

- Medication ACE-inhibitors, angiotensin receptor blockers (ARBs)
- beta-blockers, aldosterone blockers (spironolactone or eplerenone)
- Diuretics, ivabradine, digoxin (occasionally)
- Fluid restriction, daily weight
- Lifestyle changes, smoking, diet, exercise, salt
- Devices, pacemakers, CRT, ICD
- Surgery, valve, LVAD, transplant



# SURGERY

- Risk of re-operation in this group.
- Adhesions, bleeding, longer by-pass time.
- Affects renal and liver function.
- Risk of arrhythmias
- Cyanosed patient will require a higher PCV.
- Higher filling pressures needed in some conditions FBC
- Pericardial and pleural effusions may occur.

# SURGICAL EMERGENCIES

- Complications
- Bleeding, infection, fever, thrombosis, embolism, fluid overload, dehydration
- Early detection vital
- Aggressive management
- Pain control for catecholamine stress
- Avoid early discharge





# CYANOSIS

- Cyanosis results from an increase in RBC as the body attempts to improve its oxygen carrying capacity
- Increased viscosity, thrombosis, stroke, embolus, PH
- Caution if NBM, IV fluids

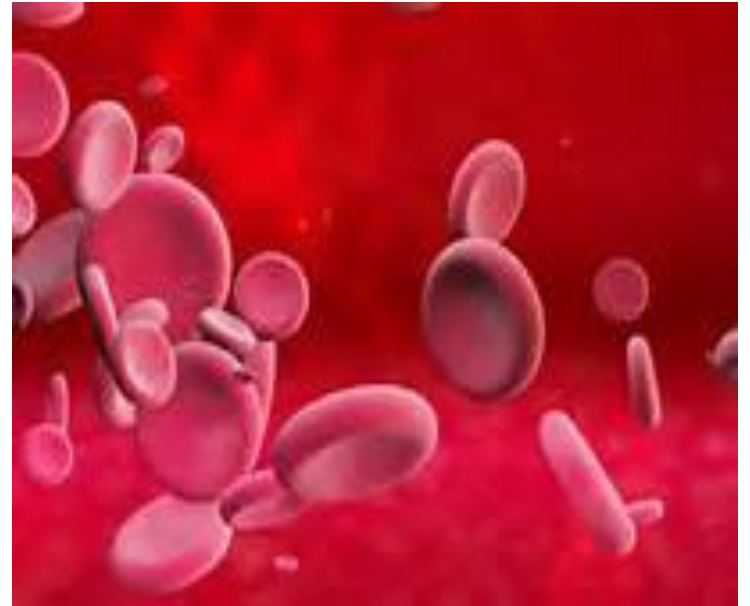
# CYANOSIS



# CYANOSIS

## Watch for.....

- Sepsis, brain abscess
- Renal function
- Gout
- Gall stones
- Orthopaedic complications
- Skin, acne, I.E.
- Ferritin



# EMERGENCIES

- Arrhythmia
- Surgery
- Cyanosis
- Infection
- Ht Failure
- Ischaemia
- Pregnancy
- Transplant

# PSYCHOLOGY

- Anxiety about heart condition, prognosis
- Repeated hospital visits
- Risk taking behaviour
- Compliance
- Depression
- Phobia
- L.D.



# Support

- Clinical experience in BHI
- Mentoring across the network
- Education/ Study pack
- Annual study days
- Regional training days
- National group BACCNA
- Support



# BACCNA

- 'British Adult Congenital Cardiac Nurses Association'
- Twice a year
- Agenda and networking
- BCCA November 14th





# LOOKING AHEAD

- 
- **Congenital networks**
  - **Support & encourage patients to lead as normal a life as their condition allows.**



Royal College  
of Nursing



RCN COMPETENCES

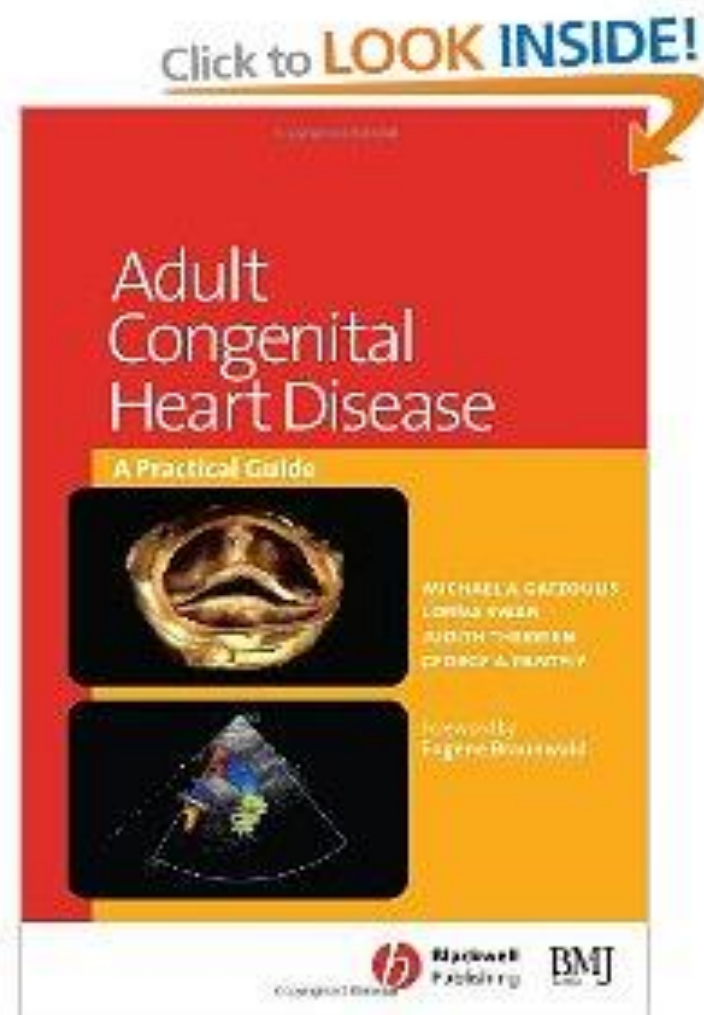
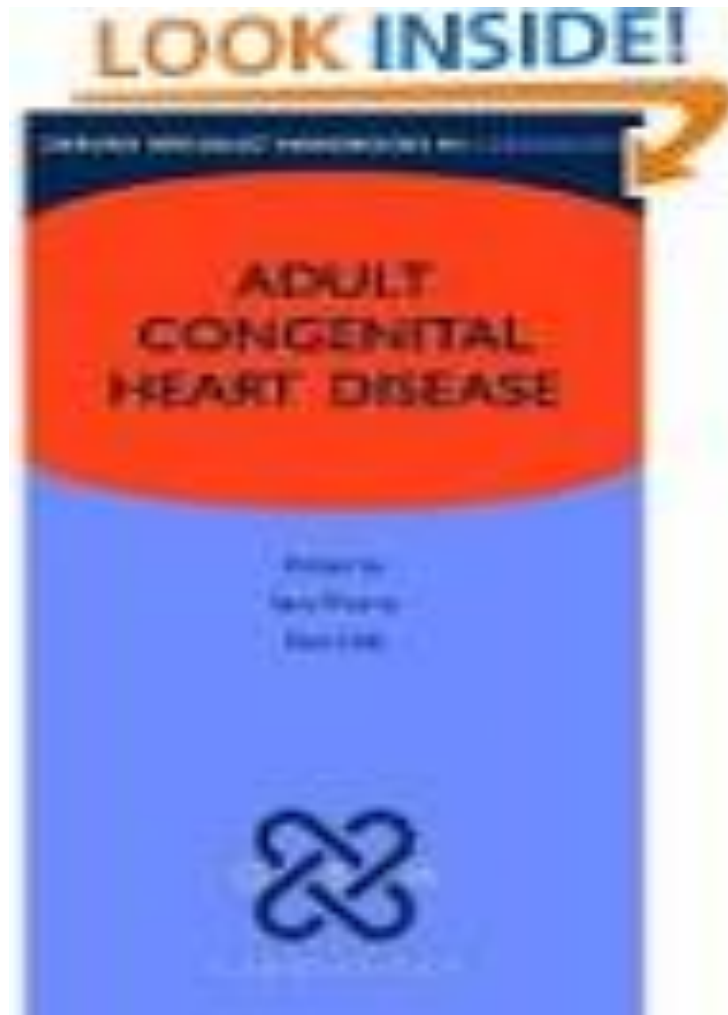
## Adult congenital heart disease nursing

*RCN guidance on roles, career pathways and competence development*

To support adult  
standards  
guidelines from  
RCN for nursing  
published



# READING





# ESC Guidelines

European Heart Journal Advance Access published August 27, 2010



European Heart Journal  
doi:10.1093/eurheartj/ehq249

ESC GUIDELINES



## ESC Guidelines for the management of grown-up congenital heart disease (new version 2010)

The Task Force on the Management of Grown-up Congenital Heart Disease of the European Society of Cardiology (ESC)

Endorsed by the Association for European Paediatric Cardiology (AEPC)

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The disclosure forms of the authors and reviewers are available on the ESC website [www.escardio.org/guidelines](http://www.escardio.org/guidelines)

ESC entities having participated in the development of this document:

**Associations:** European Association of Percutaneous Cardiovascular Interventions (EAPCI), European Heart Rhythm Association (EHRA), Heart Failure Association (HFA), European Association of Echocardiography (EAE)  
**Councils:** Cardiology Practice, Council on Primary Care, Cardiovascular Imaging, Cardiovascular Nursing and Allied Professions (CCNAP)

**Working Groups:** Grown-up Congenital Heart Disease, Pulmonary Circulation and Right Ventricular Function, Valvular Heart Disease, Cardiovascular Surgery, Thrombosis, Acute Cardiac Care

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ESC GUIDELINES



## 2015 ESC Guidelines for the management of infective endocarditis

The Task Force for the Management of Infective Endocarditis of the European Society of Cardiology (ESC)

Endorsed by: European Association for Cardio-Thoracic Surgery (EACTS), the European Association of Nuclear Medicine (EANM)

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**ESC Associations:** Acute Cardiovascular Care Association (ACCAC), European Association for Cardiovascular Prevention & Rehabilitation (EACPR), European Association of Cardiovascular Imaging (EACVI), European Heart Rhythm Association (EHRA), Heart Failure Association (HFA).

**ESC Councils:** Council for Cardiology Practice (CCP), Council on Cardiovascular Nursing and Allied Professions (CCNAP), Council on Cardiovascular Primary Care (CCPC).

**ESC Working Groups:** Cardiovascular Pharmacotherapy, Cardiovascular Surgery, Grown-up Congenital Heart Disease, Myocardial and Pericardial Diseases, Pulmonary Circulation and Right Ventricular Function, Thrombosis, Valvular Heart Disease.

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# GUIDELINES




## Adult Congenital Heart Disease

A commissioning guide for services  
for young people and Grown Ups  
with Congenital Heart Disease (GUCH)

# GUIDELINES

- European Society of Cardiology's guidelines on the “Management of Grown Up Congenital Heart Disease” 2010
- The British Cardiac Society Working Party on Grown-up congenital heart disease (GUCH). September 2002.
- The 32nd Bethesda conference: Care of the Adult with Congenital Heart Disease JACC Vol 37, 2001.
- The Canadian Cardiovascular Society's Consensus Conference update 2001 update.

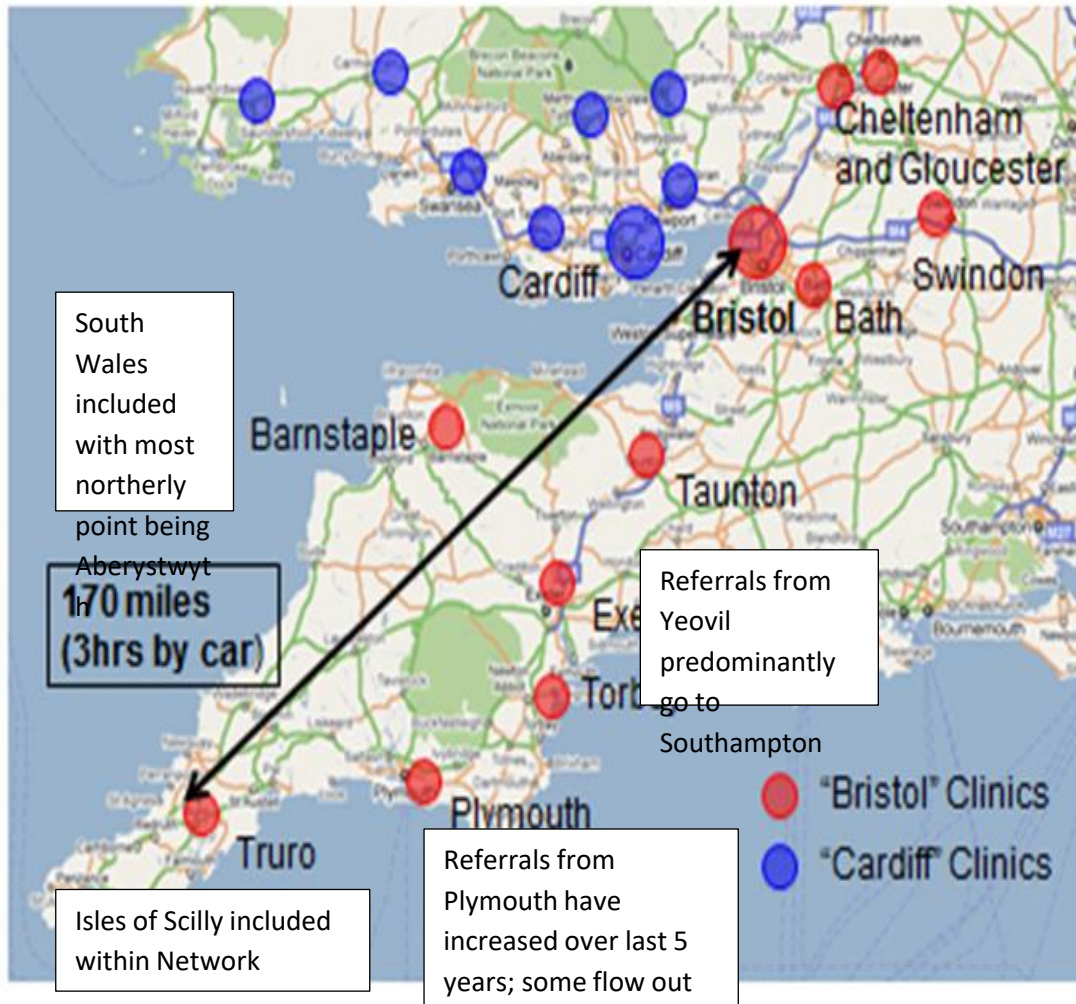
**THANK YOU!**



questions?



# Team & Geography of the Network



**Sheena Vernon,**  
Lead Nurse



**Caitlin Moss**  
Network Manager



**Dr Andrew Tometzki,**  
Clinical Director

Equity  
of  
access

Seamless care

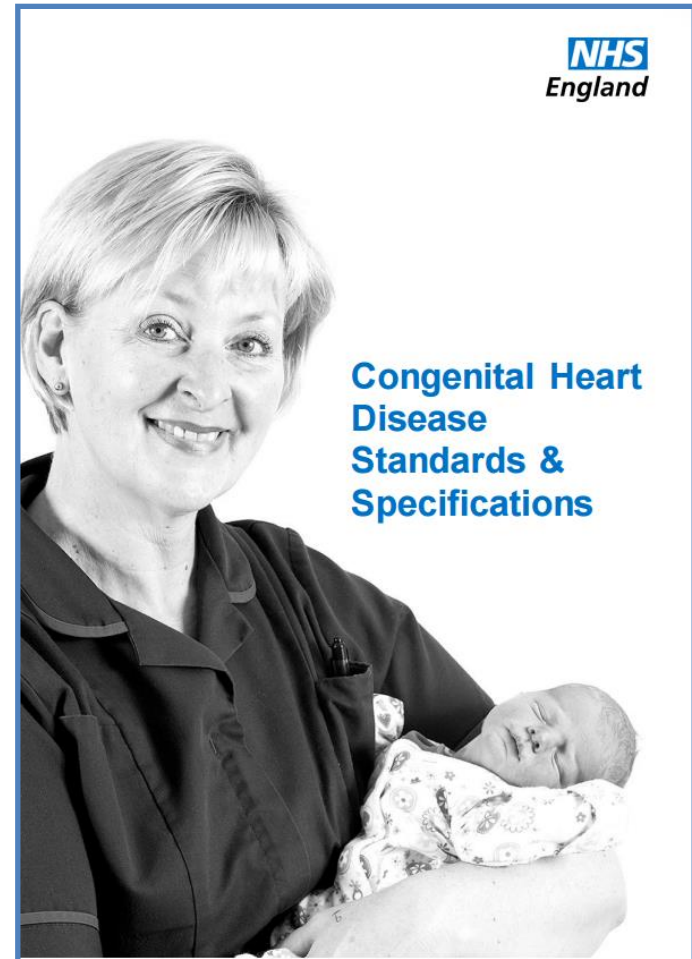
Meeting  
national  
standards

Continual  
improvement

of Network to  
Southampton  
Patient  
voice

# CHD STANDARDS

- Section A: [The network approach](#)
- Section B: [Staffing and skills](#)
- Section C: [Facilities](#)
- Section D: [Interdependencies](#)
- Section E: [Training and education](#)
- Section F: [Organisation, audit](#)
- Section G: [Research](#)
- Section H: [Communication](#)
- Section I: [Transition](#)
- Section J: [Pregnancy contraception](#)
- Section K: [Fetal diagnosis](#)
- Section L: [Palliative care and bereavement](#)



# THE NETWORK APPROACH

**sets out:** how networks will work

**new/changing:** clear leadership (clinical and professional);  
cardiology (non-surgical) centres' participation in networks;  
second opinions and referrals

- **Challenge** : communication between local, cardiology and surgical centres
- ACHD CNS from SSC or SCS provide support, education and a link to network opd and ward staff
- Local link nurse in local centre/cardiac CNS +ACHD

# TRANSITION

- **sets out** seamless pathway of care to adult services
- **new/changing:** young people to be seen at least once at transition by a specialist with ACHD expertise; clear care plans/transition passports agreed; respecting particular needs of young people with ***learning disabilities*** and their carers.

- **Challenge:**
- Big numbers
- Young adult clinics, individual time + CNS time
- Letters of introduction to patients
- In-patient and out-patient support
- Appropriate information
- Avoid loss of F/up



# Pregnancy

- Pre-pregnancy counselling for moderate to severe lesions & also:
- High risk, PH, severe Left sided lesions, Aortic root dilatation, cyanosis, ejection fraction less than 40%, mechanical valves.
- Care with ACE inhibitors, angiotensin11 receptors blockers and Amiodarone.



# PALLIATIVE CARE AND BEREAVEMENT

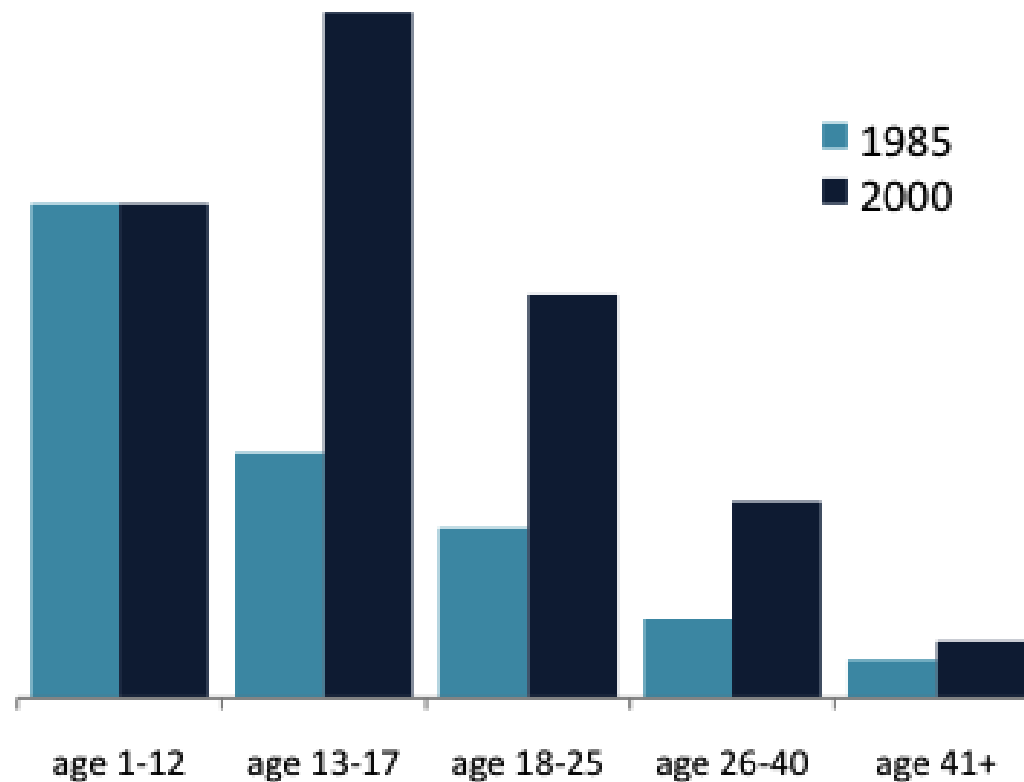
**sets out:** how to provide support at end of life and how to manage communication with families around the end of life

**new/changing:** all new

- **Challenge** : difficult conversations, patient, parents spouse, family and children
- Intense telephone advice
- End of life pathway
- Palliative care teams
- GP support

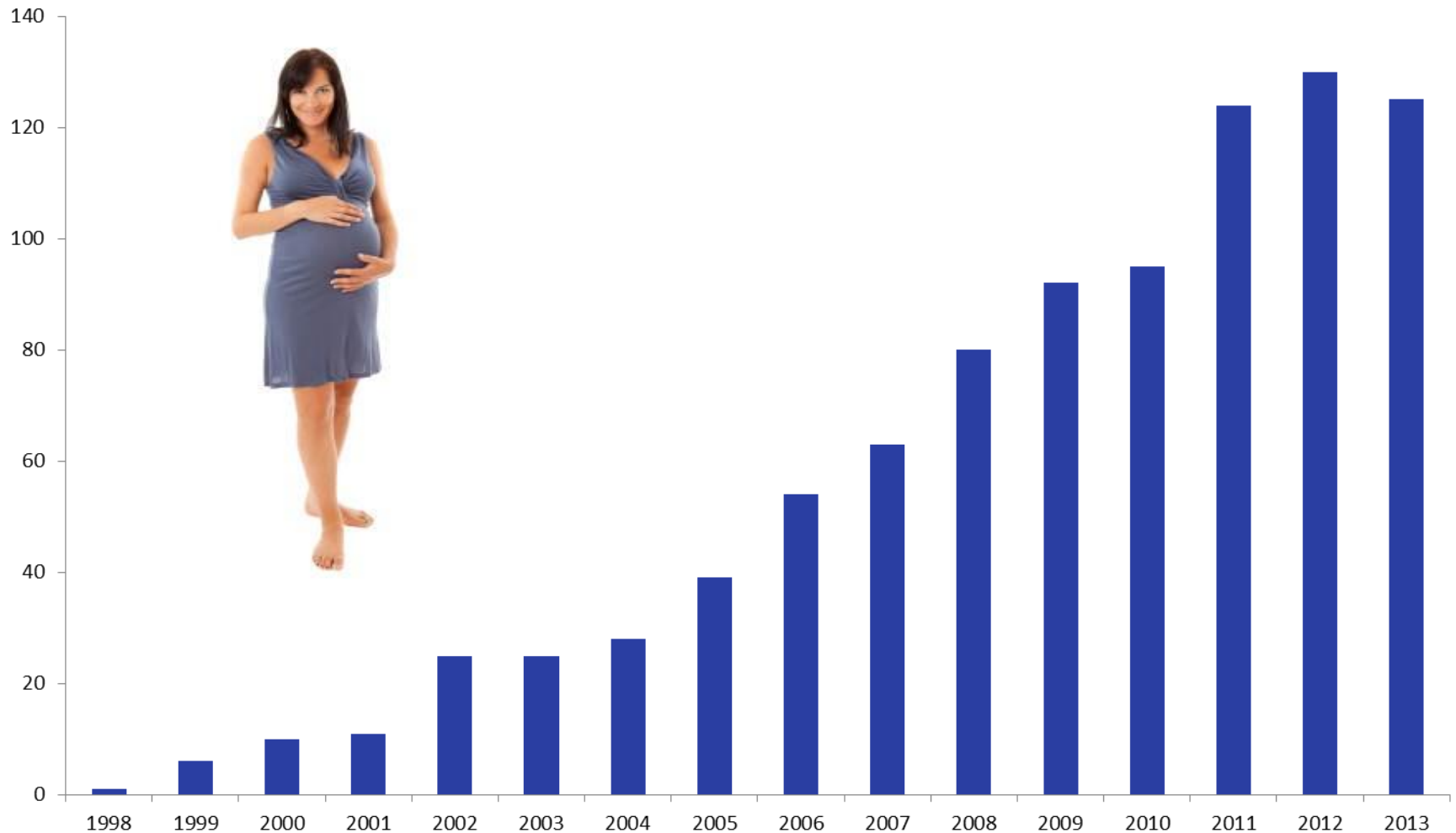


49% **adults** in 2000





# 130 new **pregnant** referrals in 2013



# Charities

- Newsletter / leaflets
- Telephone help line
- Support groups/mental health
- Financial support
- Workshops / conferences
- Web Sites
- BHF Lifestyle advice



# Coaguchek machines



- INR test
- [www.roche-diagnostic.co.uk](http://www.roche-diagnostic.co.uk)
- [www.coaguchek.co.uk](http://www.coaguchek.co.uk)

# Advice Line



# Charities

- Newsletter / leaflets
- Telephone help line
- Support groups/mental health
- Financial support
- Workshops / conferences
- Web Sites
- BHF Lifestyle advice



# PATIENT PHONE CALLS

- 2,000 calls pa admission, surgery, intervention, pregnancy, learning disability, TYA. Advice for HC professionals.
- Support, bereavement.
- Long haul flights/ travel.
- Employment issues/benefits.
- Managing Warfarin – INR – Coagu check.
- Tel. Pre-op.

# PATIENT PHONE CALLS

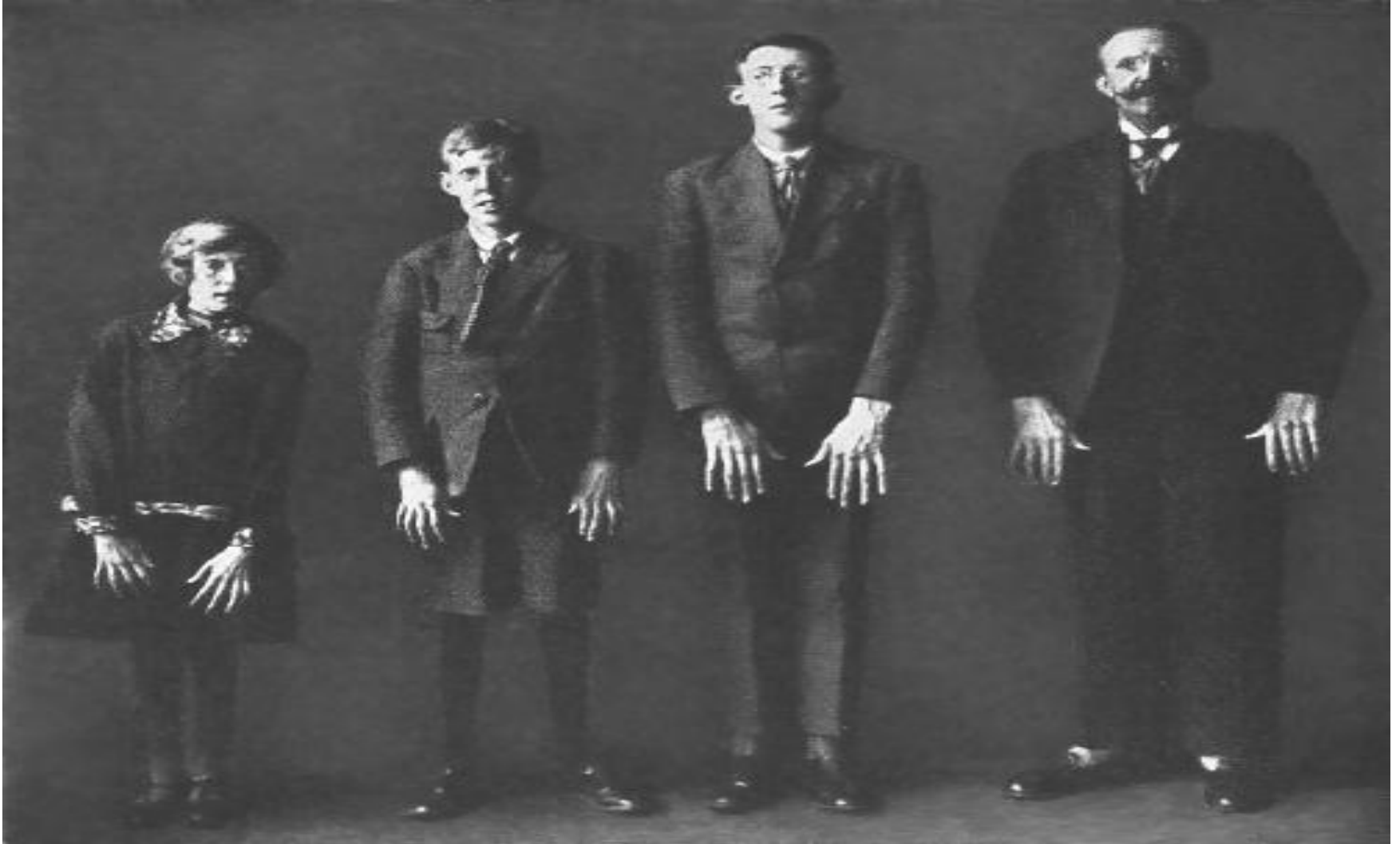
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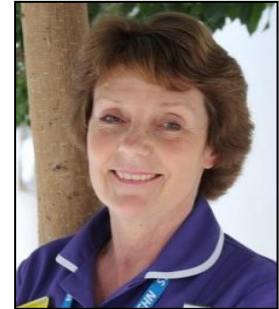
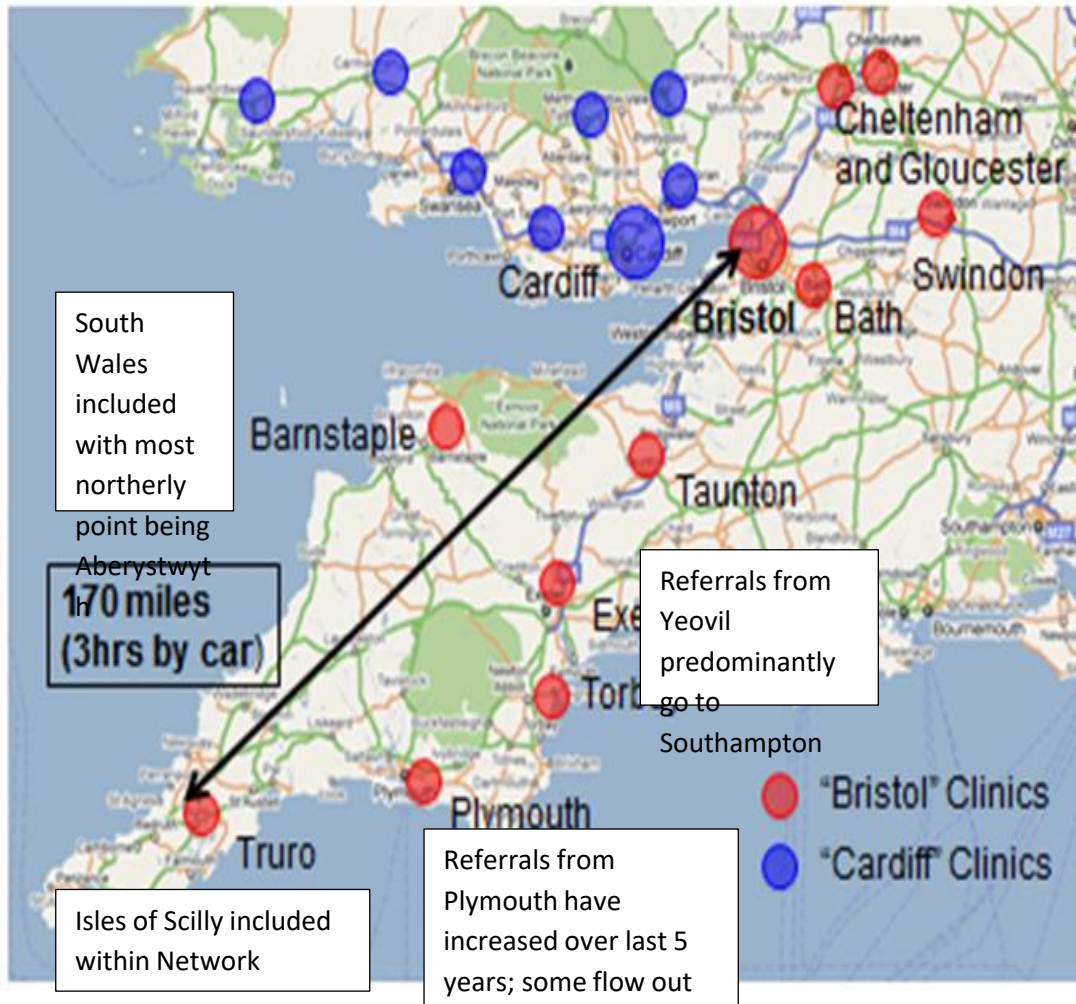
# Piercings



# MARFANS SYNDROME



# Team & Geography of the Network



**Sheena Vernon,**  
Lead Nurse



**Caitlin Moss**  
Network Manager



**Dr Andrew Tometzki,**  
Clinical Director

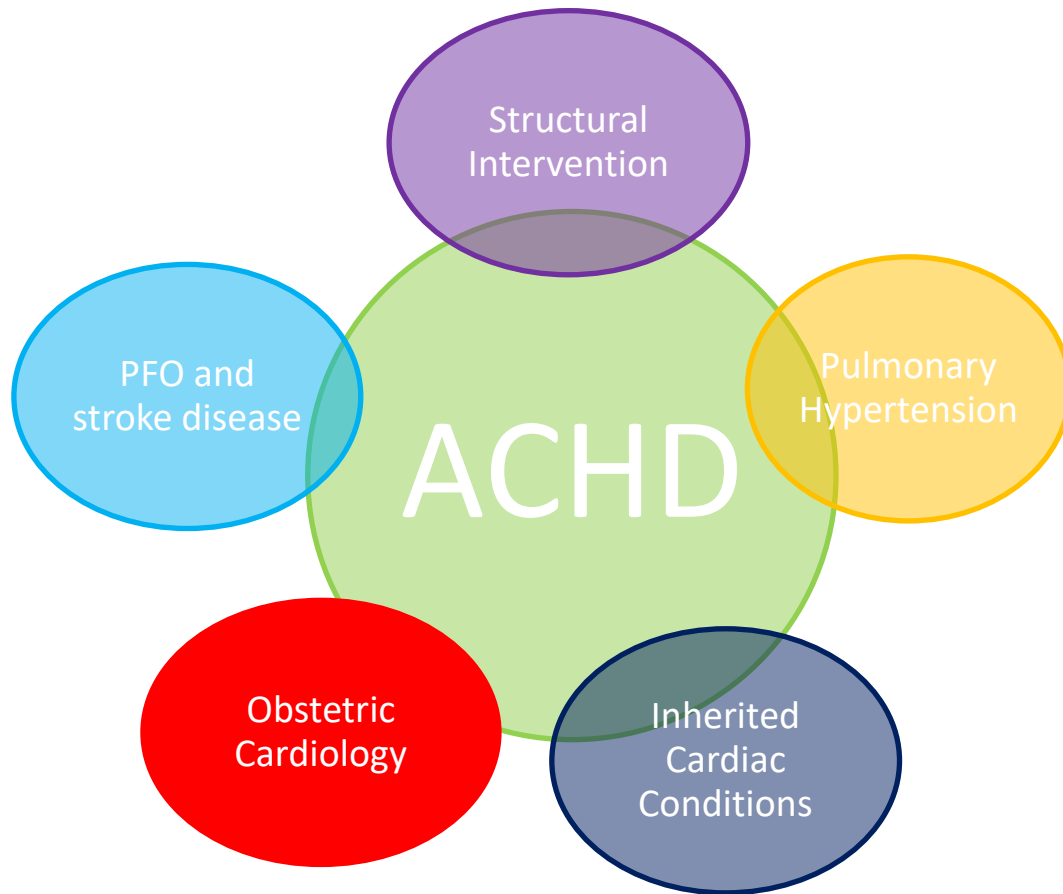
Equity  
of  
access

Seamless care

Meeting  
national  
standards

Continual  
improvement

of Network to  
Southampton  
Patient  
voice





# Learning Disabilities

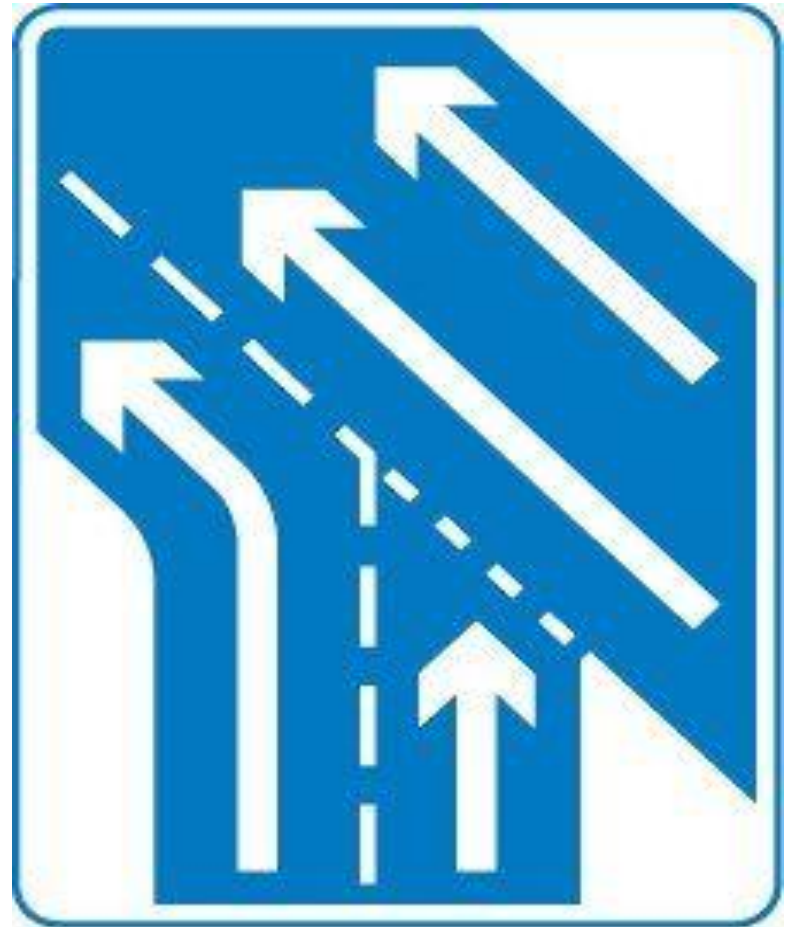
- Increasing numbers of patients having procedures and treatment
- 1 in 700 born with Downs, 40% will have CHD
- Time consuming
- Support for patient, family, CLDT and carers
- Capacity to consent? Best interest meetings?
- Appropriate communication

# NURSING TEAM OF THE YEAR 2014



# Lifestyle issue

- Outline of population
- Diet, alcohol, smoking and drugs
- Endocarditis
- Exercise
- Sex, pregnancy and contraception
- Extreme sport
- Risk taking
- Travel
- Support





# Arrhythmias

- Causes
- Precipitating factors
- Deterioration
- Treatment
- Structural v Electrical
- Haemodynamics
- SVT most common
- VT in AS + TOF

