

An Overview Common Congenital Heart Conditions

Sheena Vernon MSc
Lead Nurse CHD Network
Psychology Day 2020

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	20%

PREDISPOSING FACTORS

- Maternal drugs e.g. anti-epileptics, lithium, alcohol
- Chromosomal Aberrations e.g. 1 in 700 Downs 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



Lesion information on all lesions on www.swswchd.co.uk

Professionals→Clinical information→adults



University Hospitals Bristol 
NHS Foundation Trust

Fontan Circulation (Total cavopulmonary circulation (TCPC))

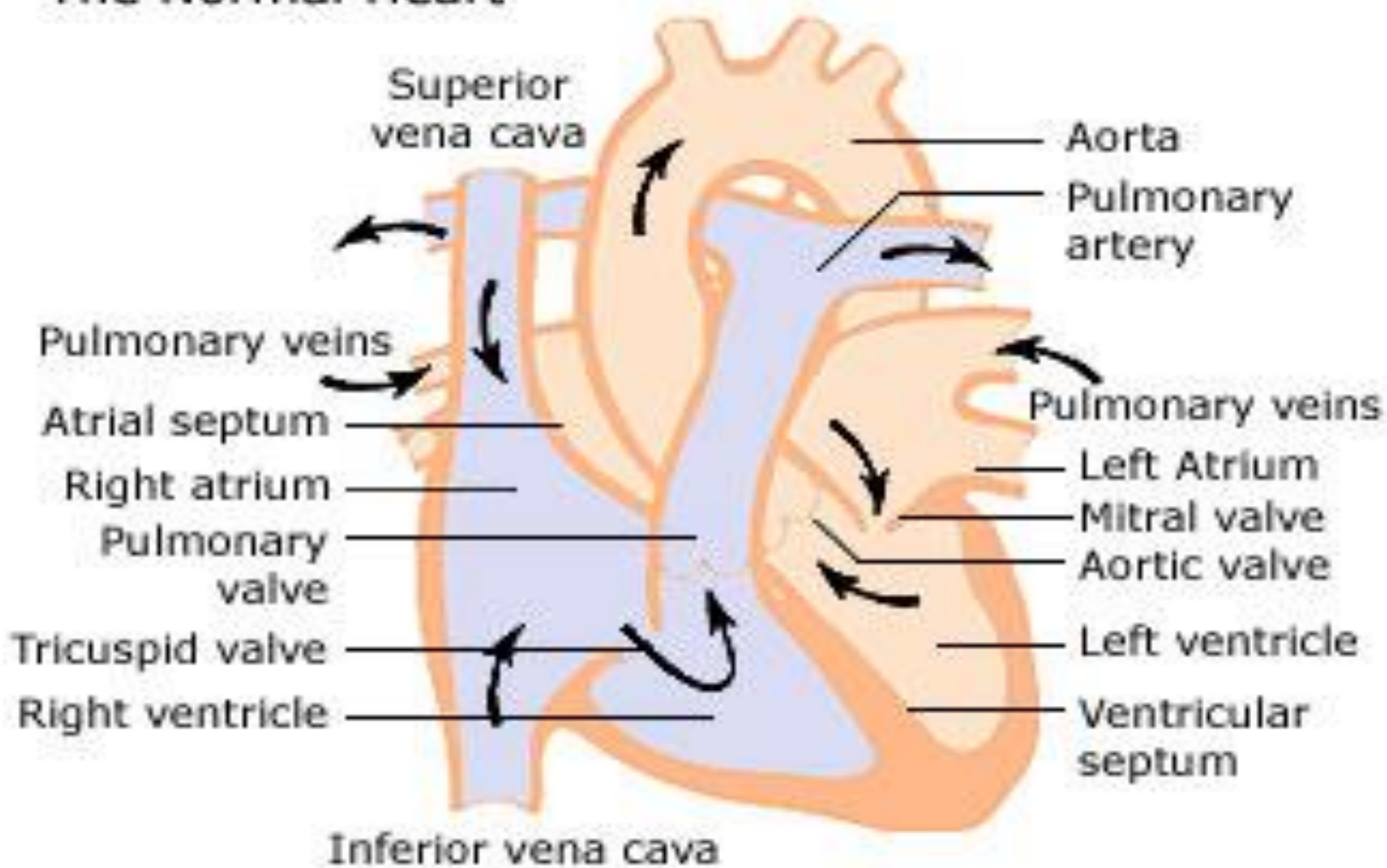
SETTING	South West England and South Wales
GUIDELINE FOR	Cardiology teams in South West England and South Wales hospitals
PATIENT GROUP	Adult patients with congenital heart disease

GUIDANCE

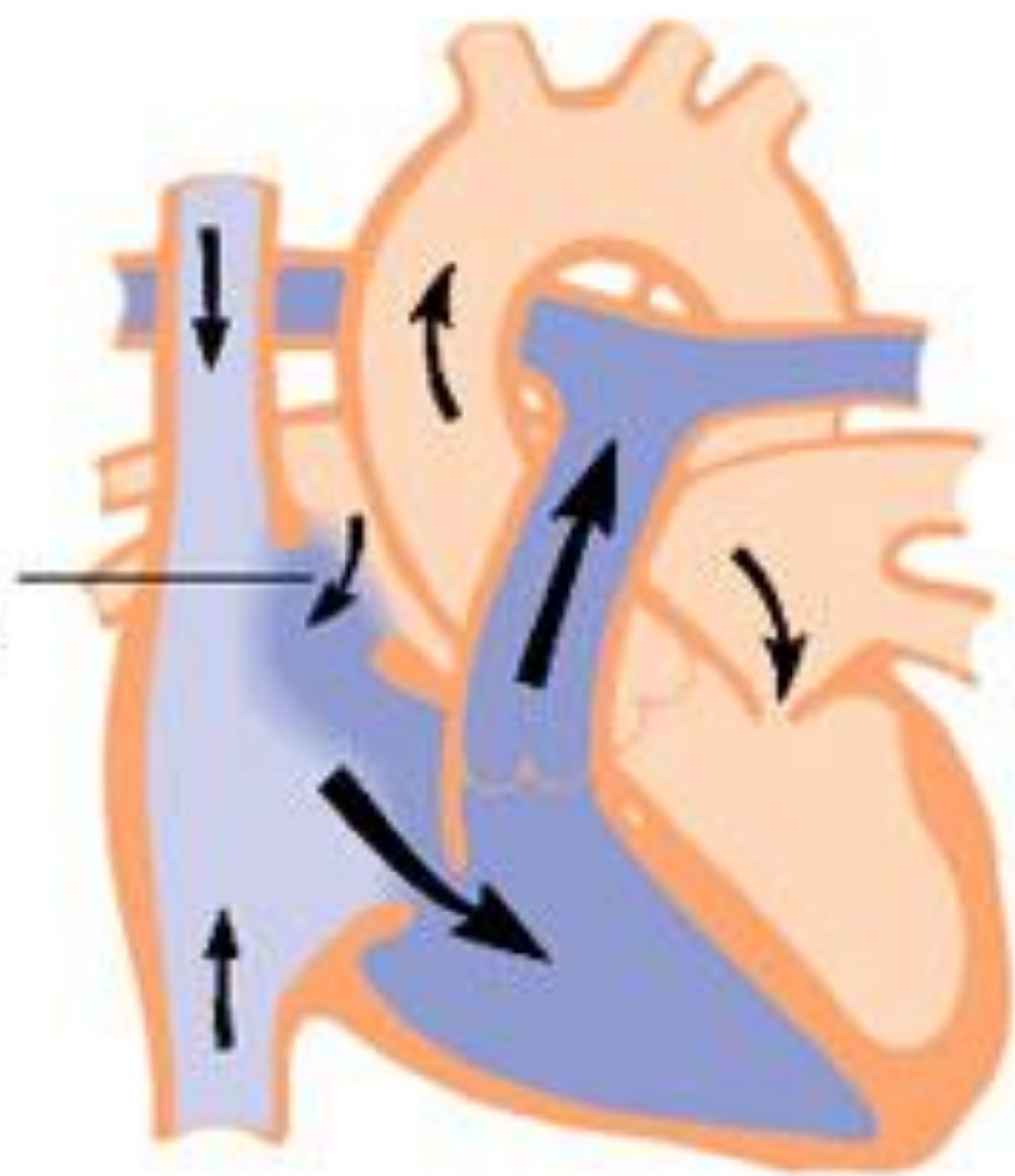
Follow-up:	annual
Associated lesions:	dependent on the underlying abnormality, note may be isomerism
Inheritance:	dependent on the underlying abnormality

Long-term complications:

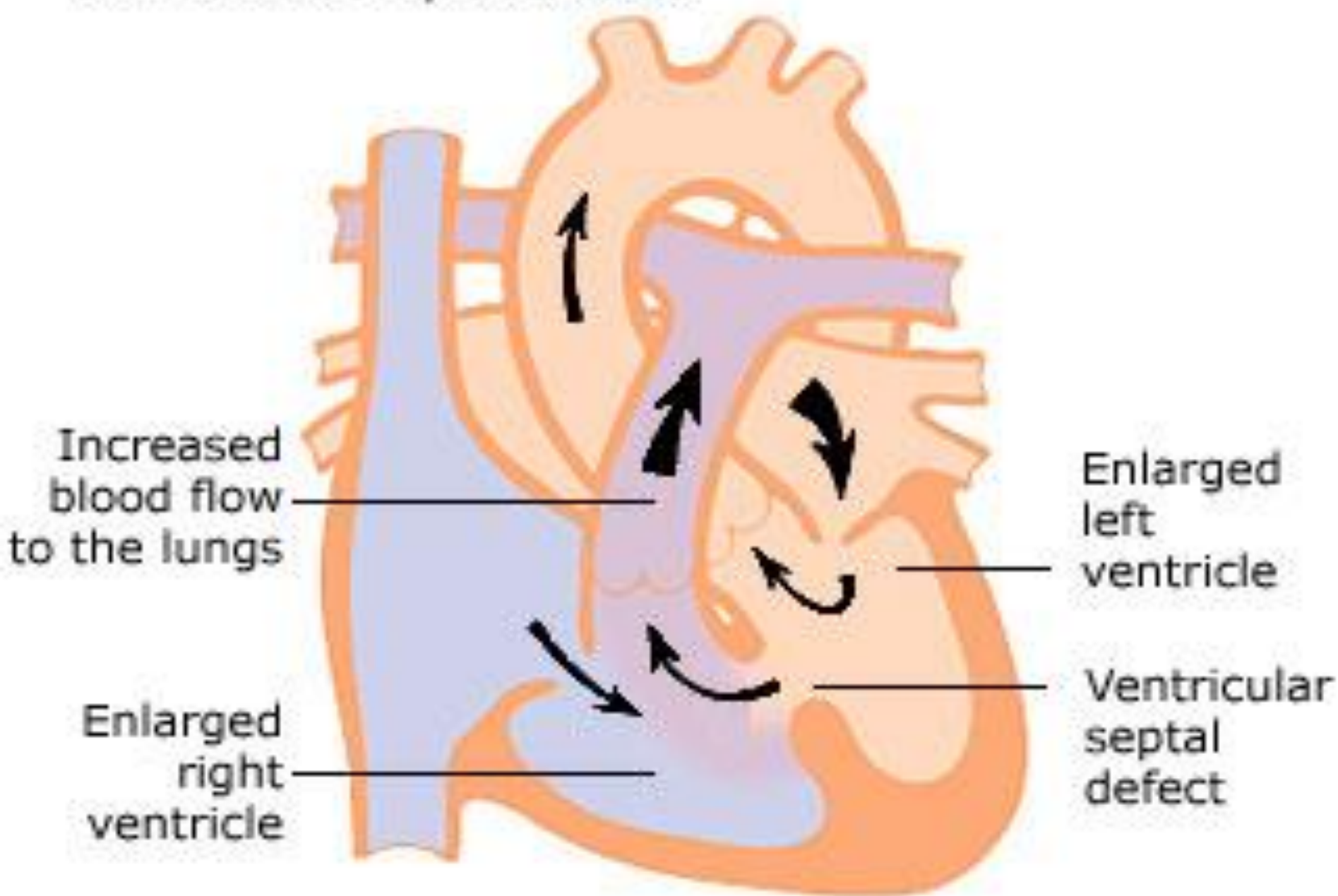
The Normal Heart



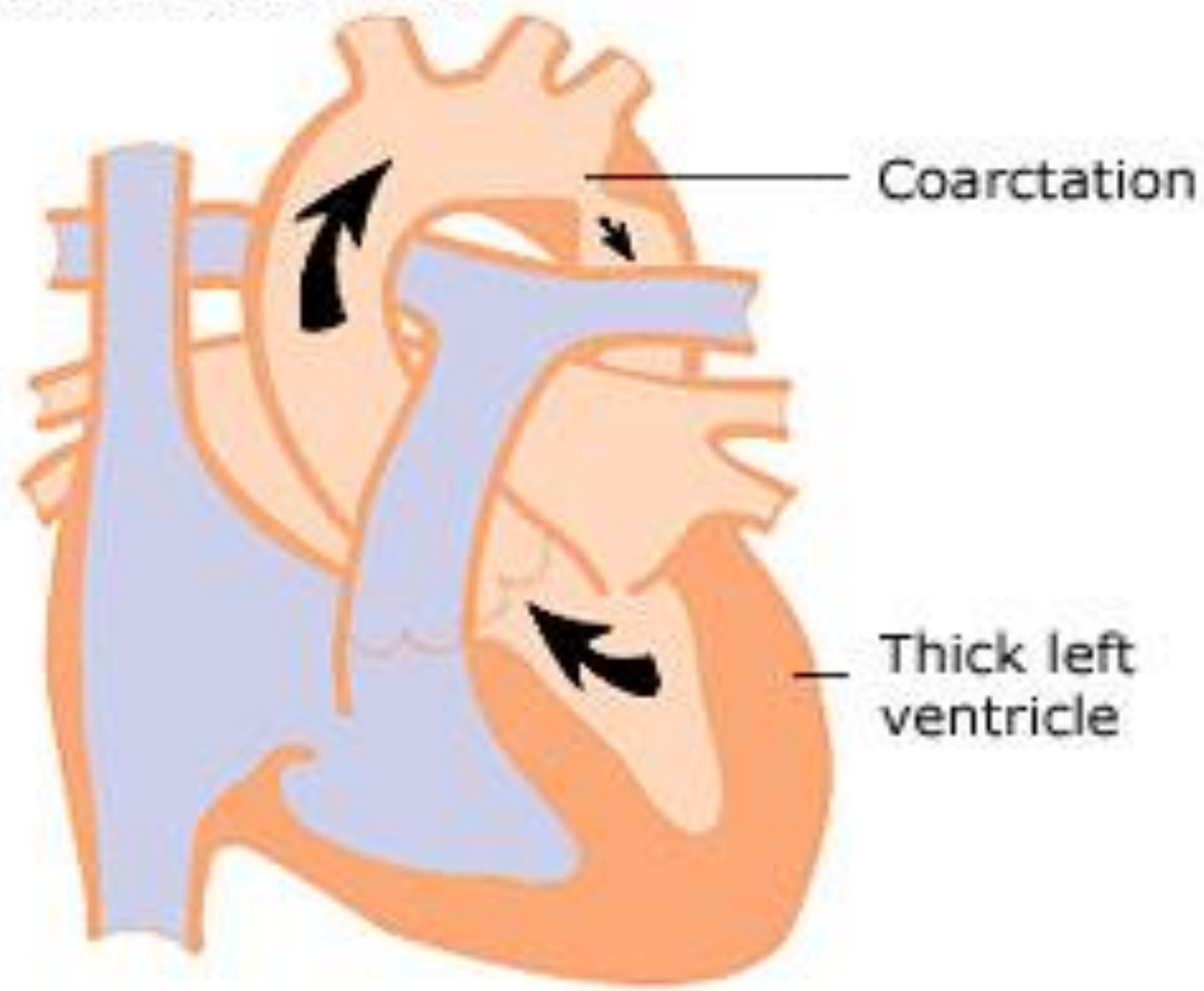
Atrial septal defect



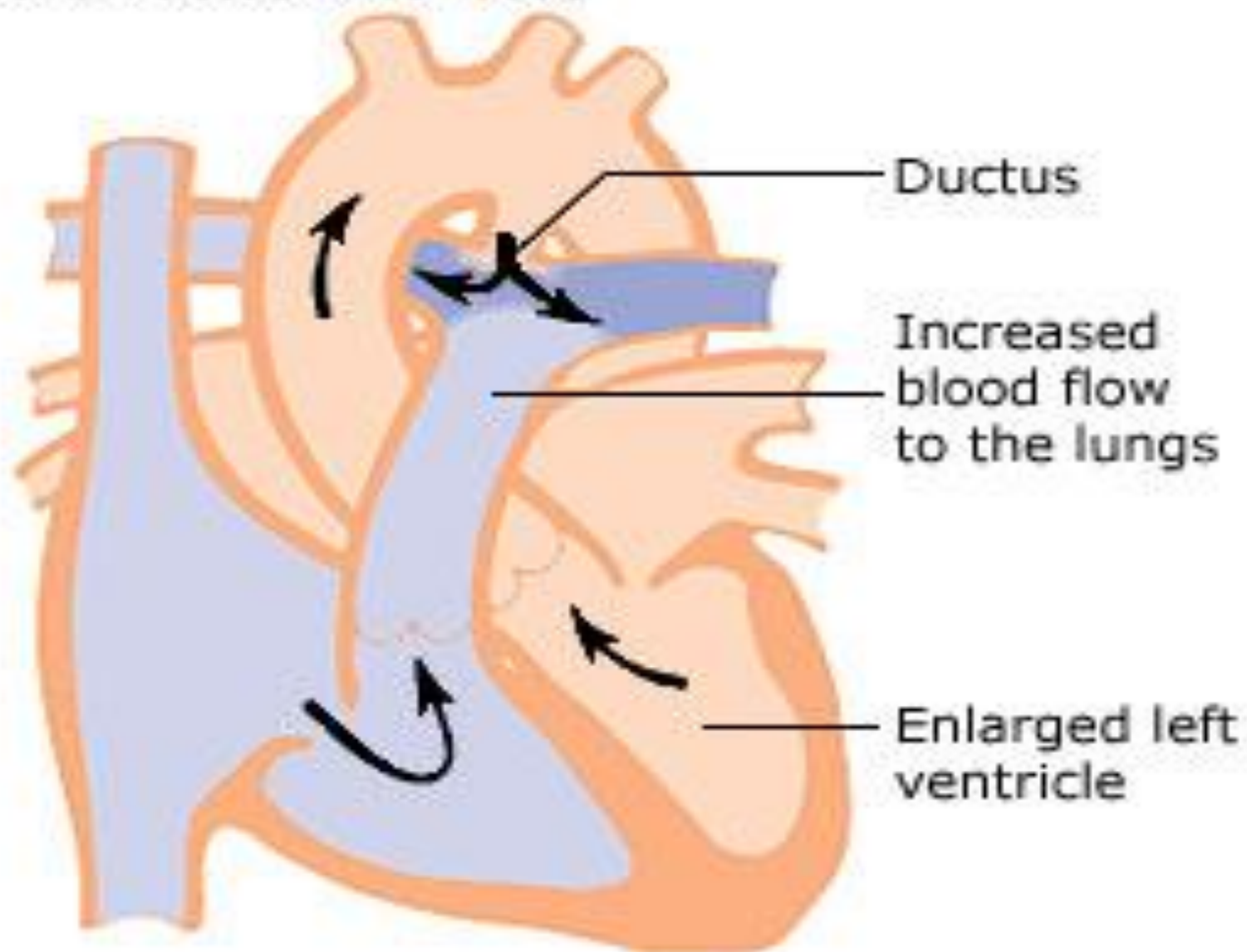
Ventricular Septal Defect



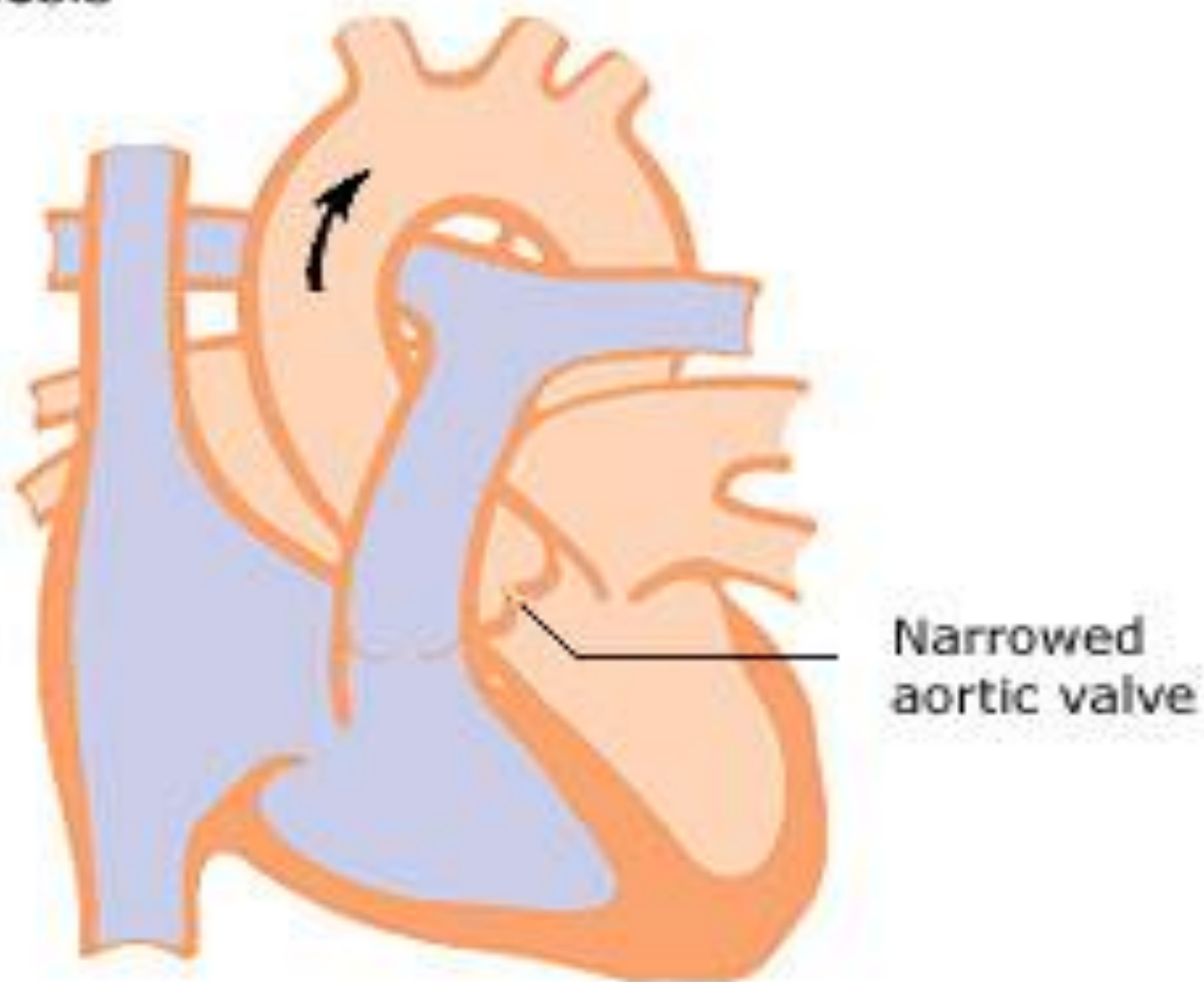
Coarctation of the Aorta



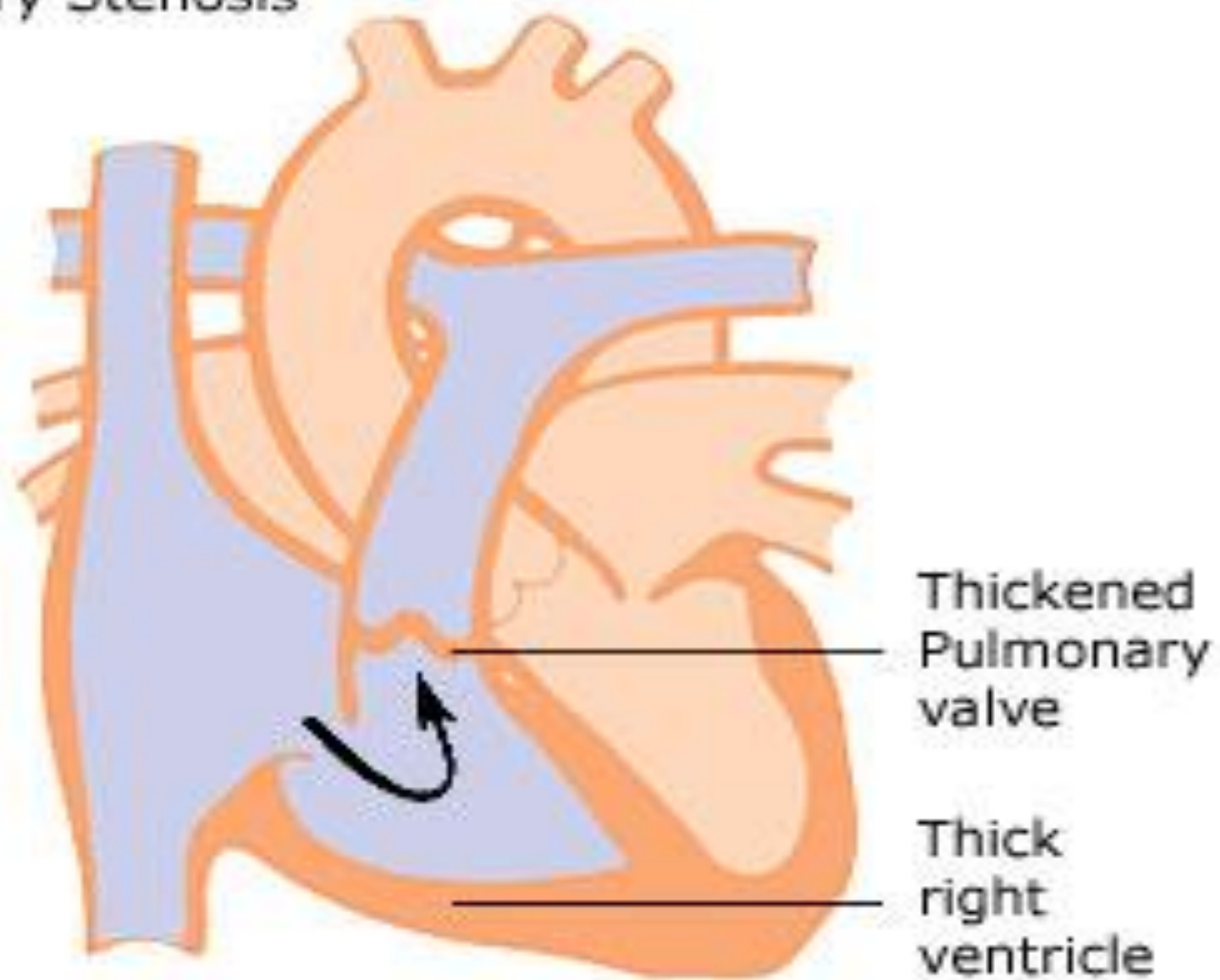
Persistent Ductus Arteriosus



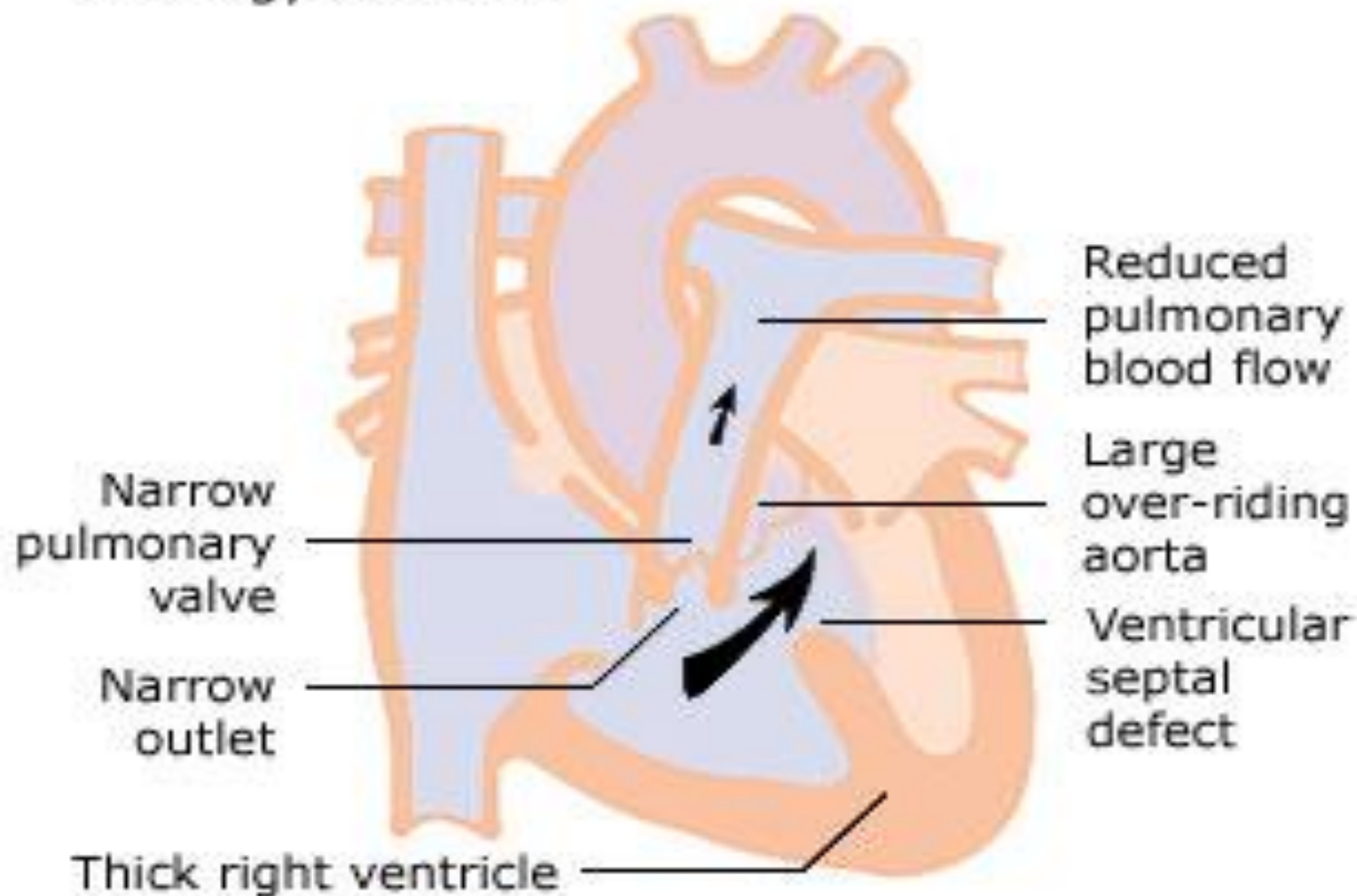
Aortic stenosis



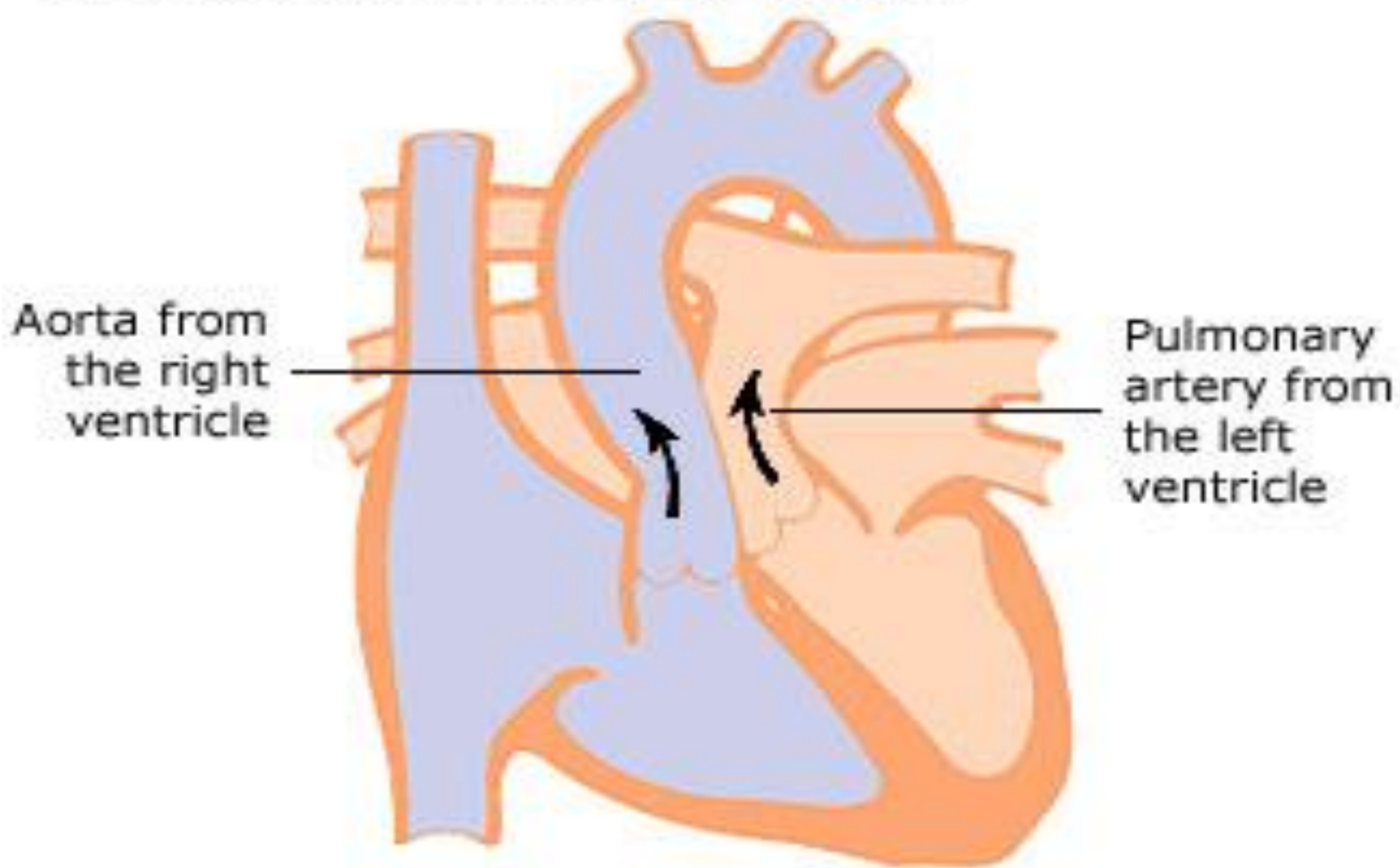
Pulmonary Stenosis



Tetralogy of Fallot



Transposition of the Great Arteries



PHYSICAL ASPECTS OF CARE

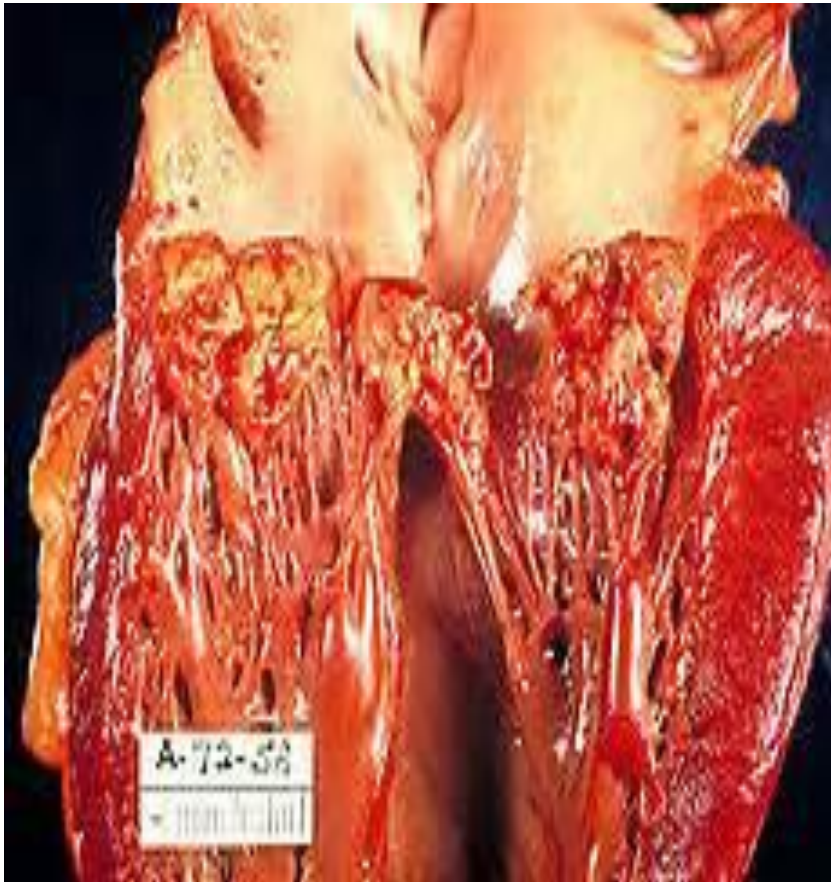
- Infective endocarditis.
- Arrhythmias/heart failure.
- Surgery +/- re-operation – risks Intervention.
- Stroke.
- Cyanosis/Polycythaemia.
- Pregnancy/Contraception.
- Coronary Artery Disease.

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



SURGICAL PROBLEMS

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

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

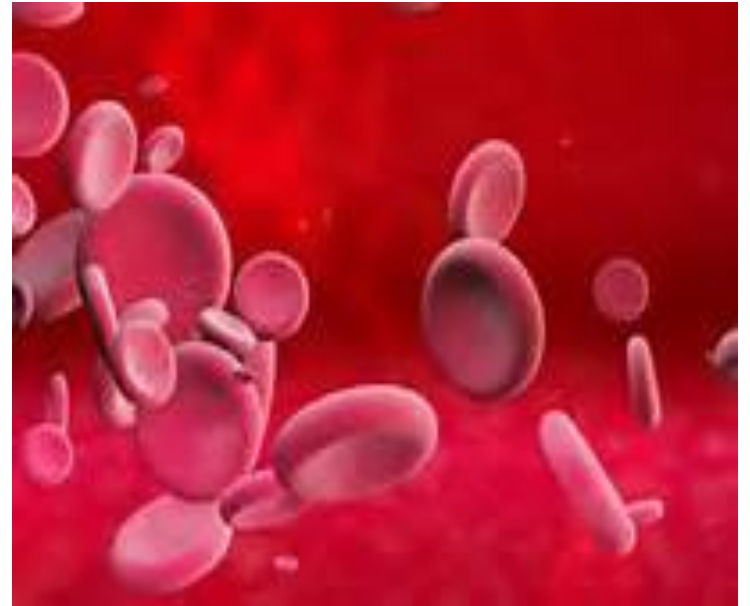
CYANOSIS



CYANOSIS

Watch for.....

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

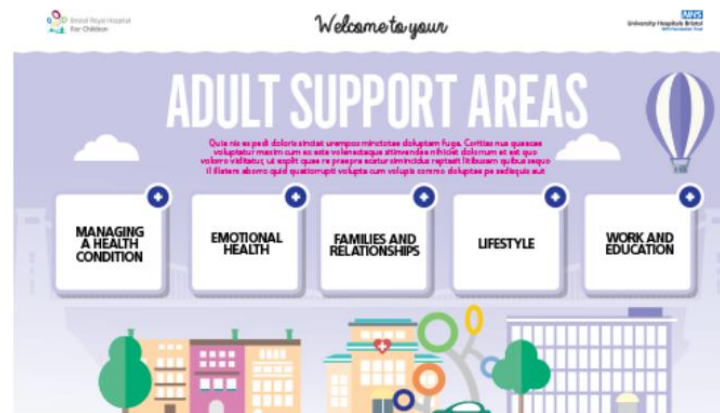


EMERGENCIES

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

PSYCHOLOGY

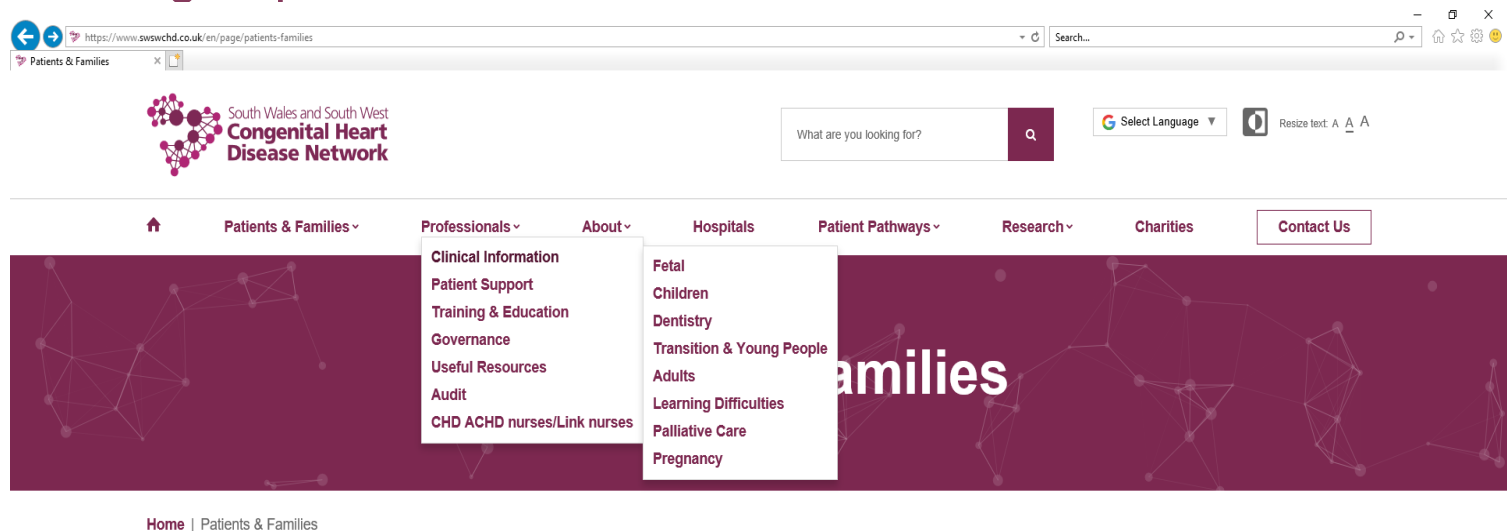
- Anxiety about heart condition, prognosis
- Repeated hospital visits
- Risk taking behaviour
- Compliance
- Depression
- Phobia
- L.D.
- Toolkits on website for patients www.swswchd.co.uk



Patients & Families

Support

- Clinical experience in Level 1, mentoring across the network
- Education/ Study pack-link nurse resources
- Annual and regional study days
- National group BACCNA



This section of the website is dedicated to patients and their families/carers. Here we hope you will find lots of resources that are useful to you.


We have shared some **Patient Stories** for you to read. If you would like to add your story to our website, please **Contact Us**

The **Leaflets** section contains online versions of many leaflets relevant to a congenital heart condition that we hope you find useful. (If you are a professional with a new leaflet you'd like to add, please get in touch with Sheena.Vernon@uhbristol.nhs.uk).



Resources


- <https://www.newachdlearningcenter.org/>



Heart
UNIVERSITY

Adult Congenital Heart Disease
LEARNING CENTER

[Home](#) [Login/Register](#) [Team](#) [Communication](#) [PCLC Learning Center](#)



Lesion-Specific
Topics

GUIDELINES & REFERENCES

- + Adult Congenital Heart Disease (ACHD)
- + Adult Congenital Heart Disease Glossary of Terms
- + Aortic Disease
- + Arterial Hypertension
- + Cardiac Catheterization
- + Echocardiography
- + Electrophysiology
- + Exercise
- + Genetics
- + Heart Failure & Transplant
- + Imaging
- + Infective Endocarditis
- + Pulmonary Hypertension

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

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 entities having participated in the development of this document:

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

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THANK YOU!



questions?

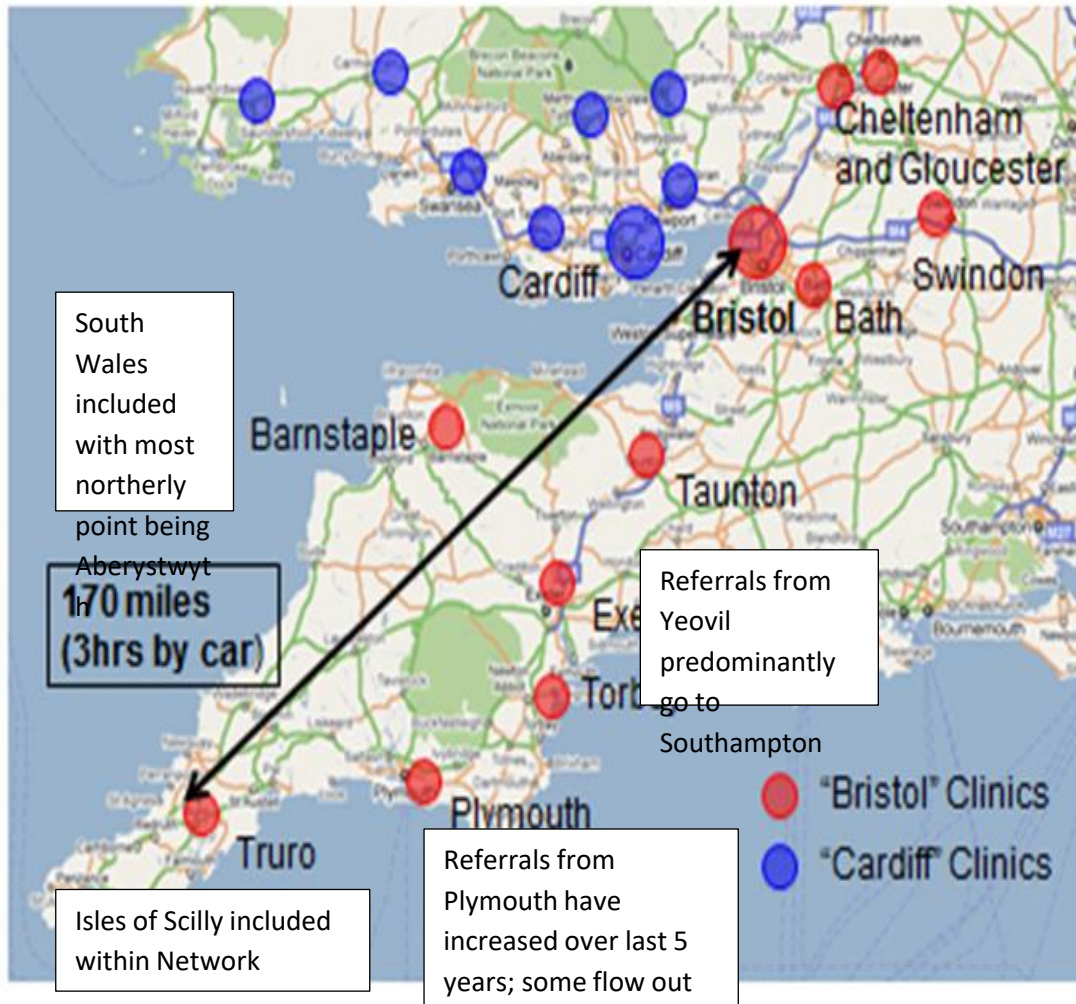
GUIDELINES



Adult Congenital Heart Disease

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

Team & Geography of the Network



Sheena Vernon,
Lead Nurse



Caitlin Moss
Network Manager



Dr Andrew Tometzki,
Clinical Director

Equity
of
access

Seamless
care

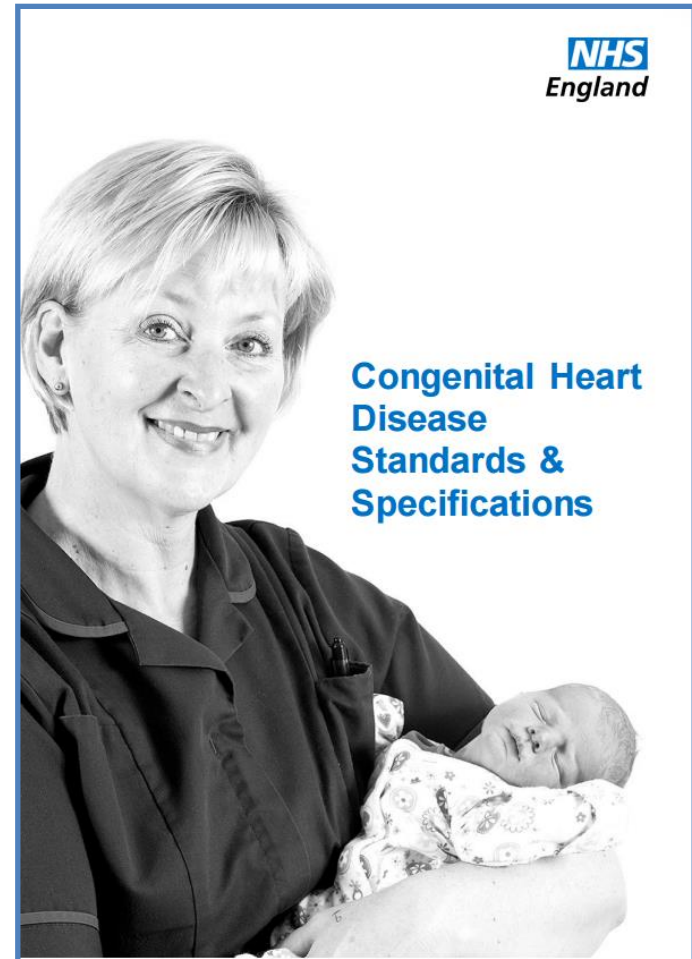
Meeting
national
standards

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

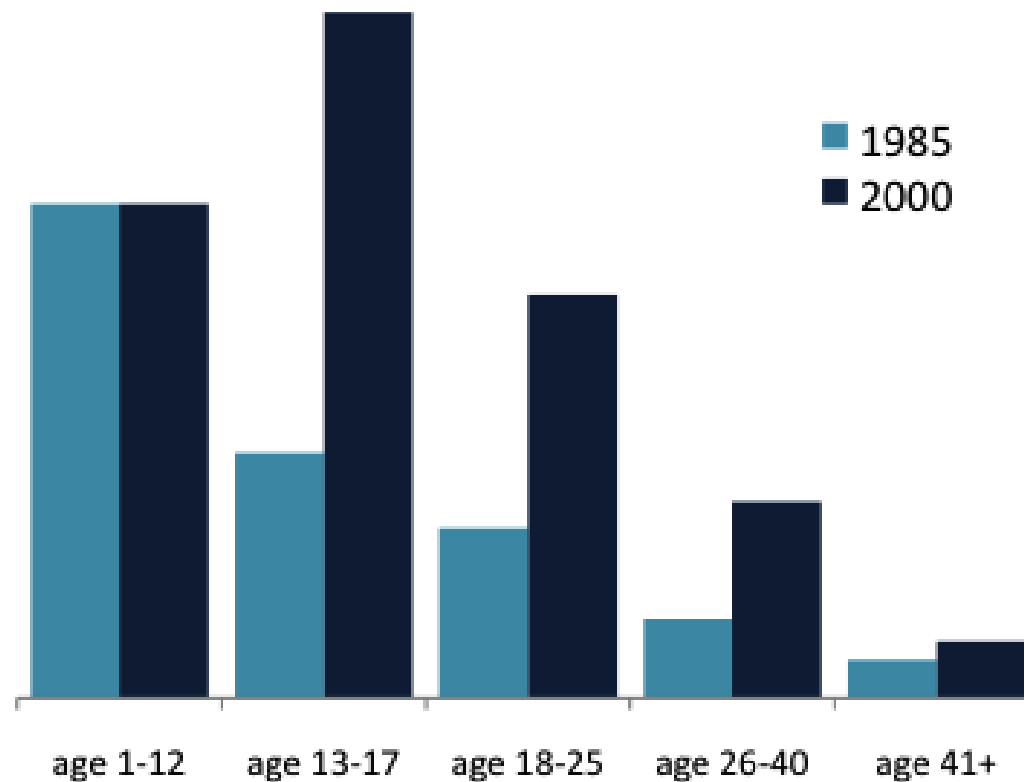
sets out: how to provide support at end of life and how to manage communication with families around the end of life

new/changing: all new

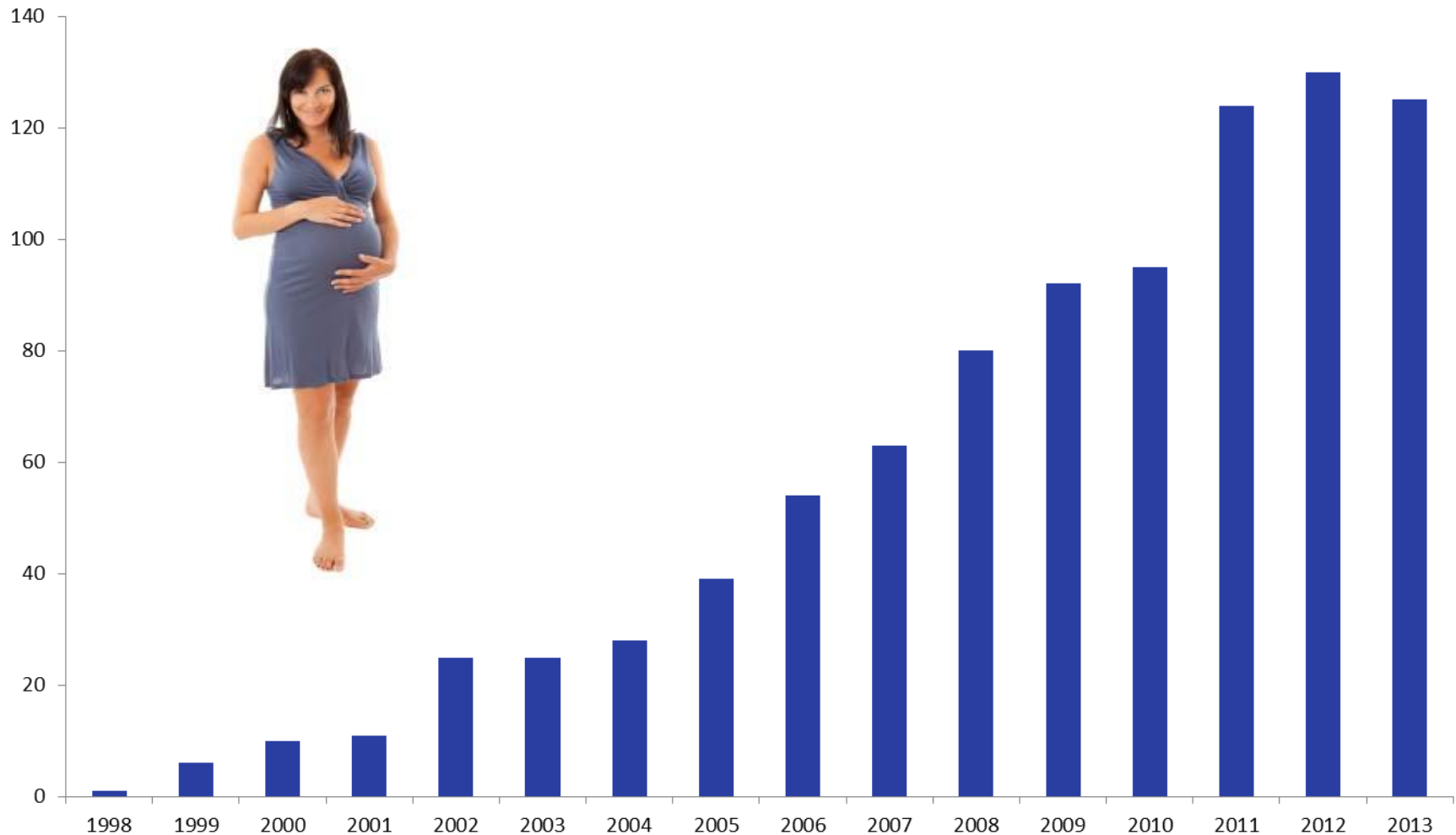
- **Challenge** : difficult conversations, patient, parents spouse, family and children
- Intense telephone advice
- End of life pathway
- Palliative care teams
- GP support



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
- 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.

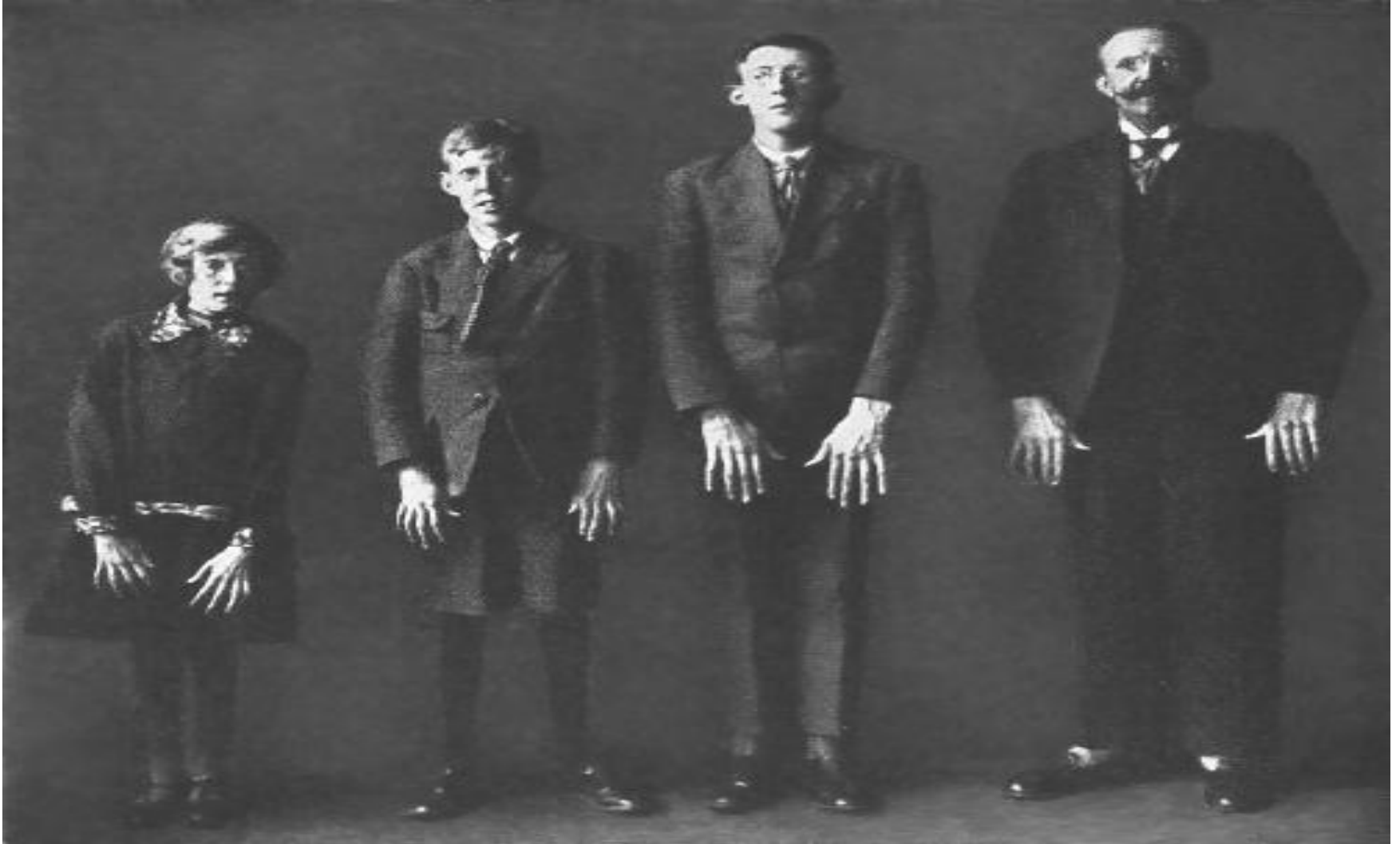
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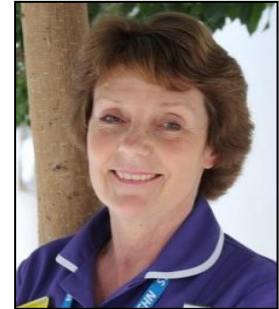
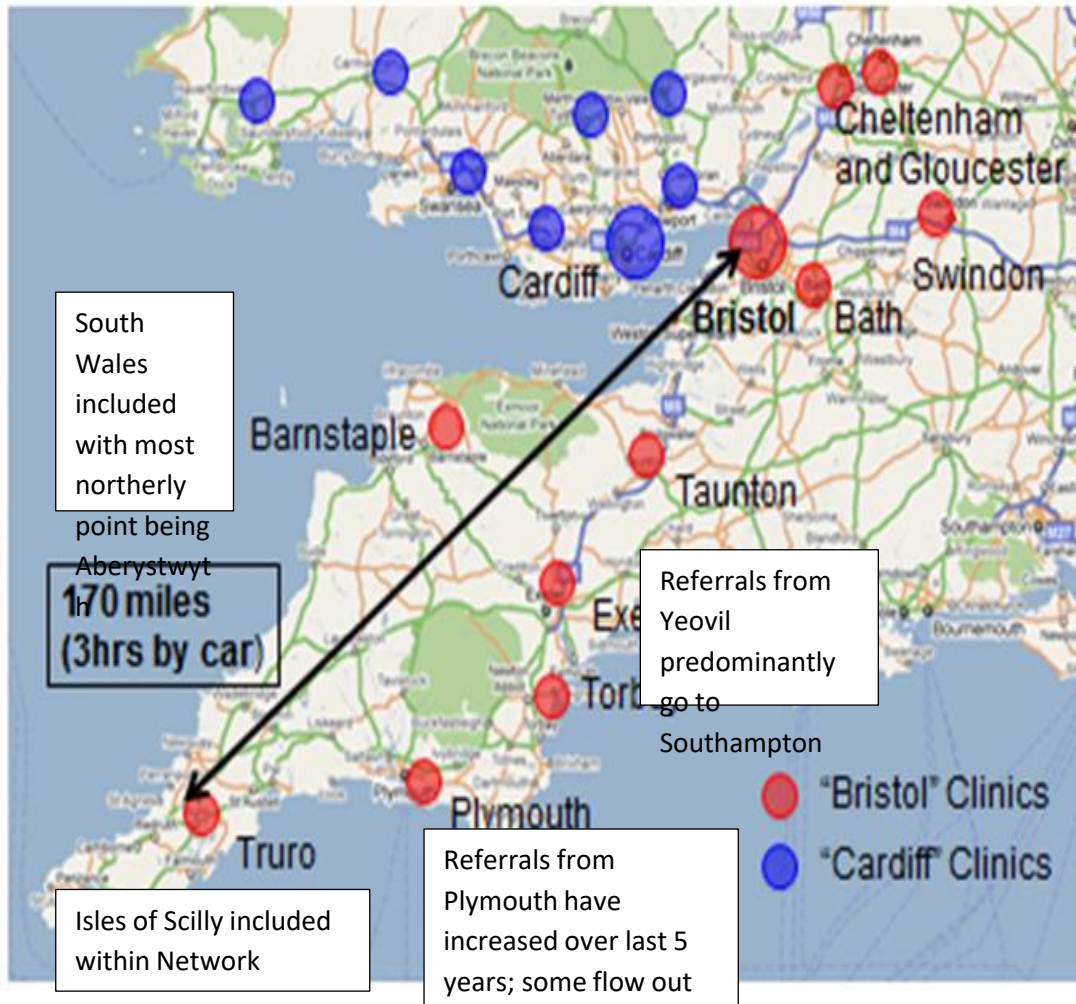
Piercings



MARFANS SYNDROME



Team & Geography of the Network



Sheena Vernon,
Lead Nurse



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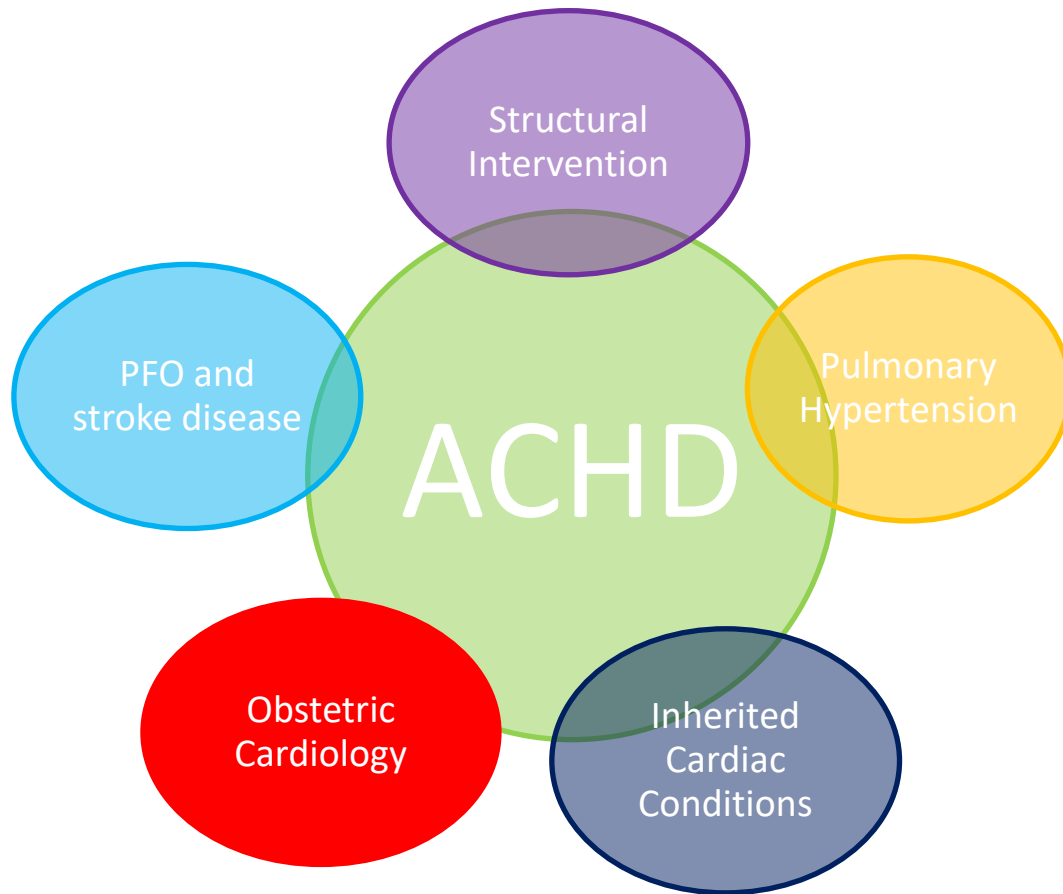
Equity
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access

Seamless
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Meeting
national
standards

Continual
improvement

of Network to
Southampton
Patient
voice



Learning Disabilities

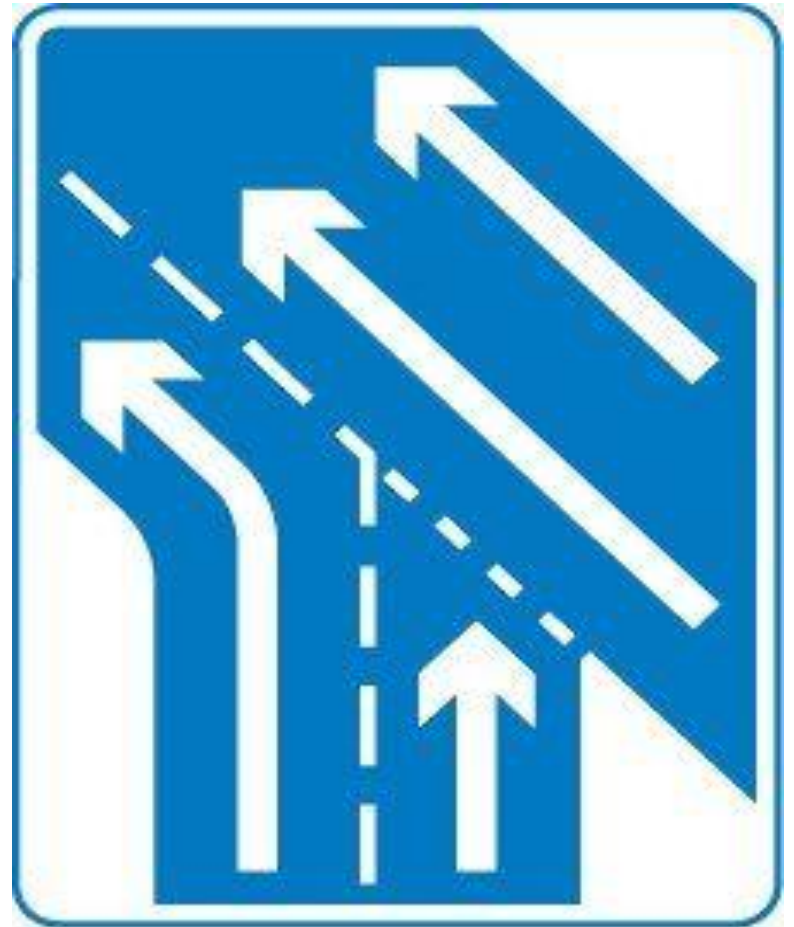
- Increasing numbers of patients having procedures and treatment
- 1 in 700 born with Downs, 40% will have CHD
- Time consuming
- Support for patient, family, CLDT and carers
- Capacity to consent? Best interest meetings?
- Appropriate communication

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



ADVICE LINE



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

