



# Cleft Lip and Palate Update NORTH WALES 2022



North West England, the Isle of Man and North Wales  
Cleft Lip and Palate Network



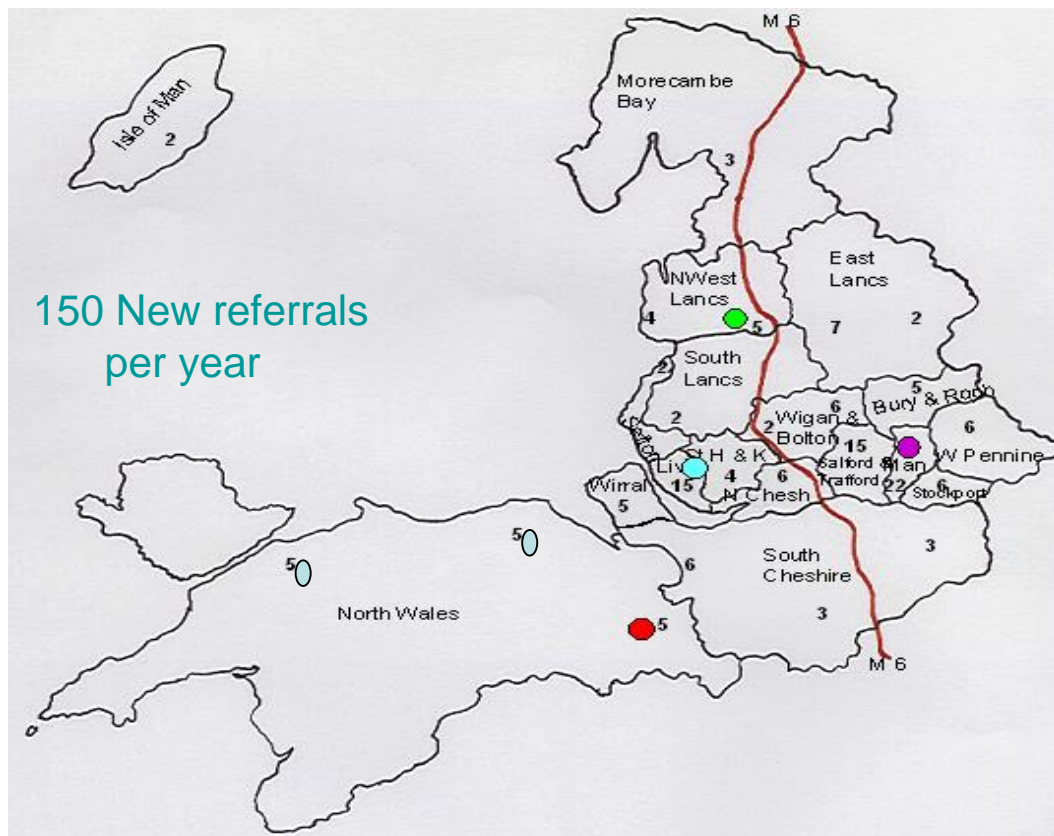


# Aims

- Service Overview
- Cleft Palate & Cleft Lip (+ Antenatal Care)
- Impact of Cleft on Baby and Family
- Best Practice Guidelines
- Referral pathways to Cleft Team
- MDT care
- Cleft in North Wales
- Jess and Toby's Story



# North West, Isle of Man & North Wales Cleft Network



## Surgical hubs

Liverpool and Manchester

## CNS locations

- Liverpool
- Manchester

Outreach  
Preston and  
Wales

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# Multiple Disciplinary Care

- Hospital of birth
- Clinical Nurse Specialist
- Surgeon
- Speech and Language Therapist
- Dentist/Dental Therapist
- Orthodontist
- Psychologist
- Audiologist



## Incidence of clefting

1 in **650 -700** live births

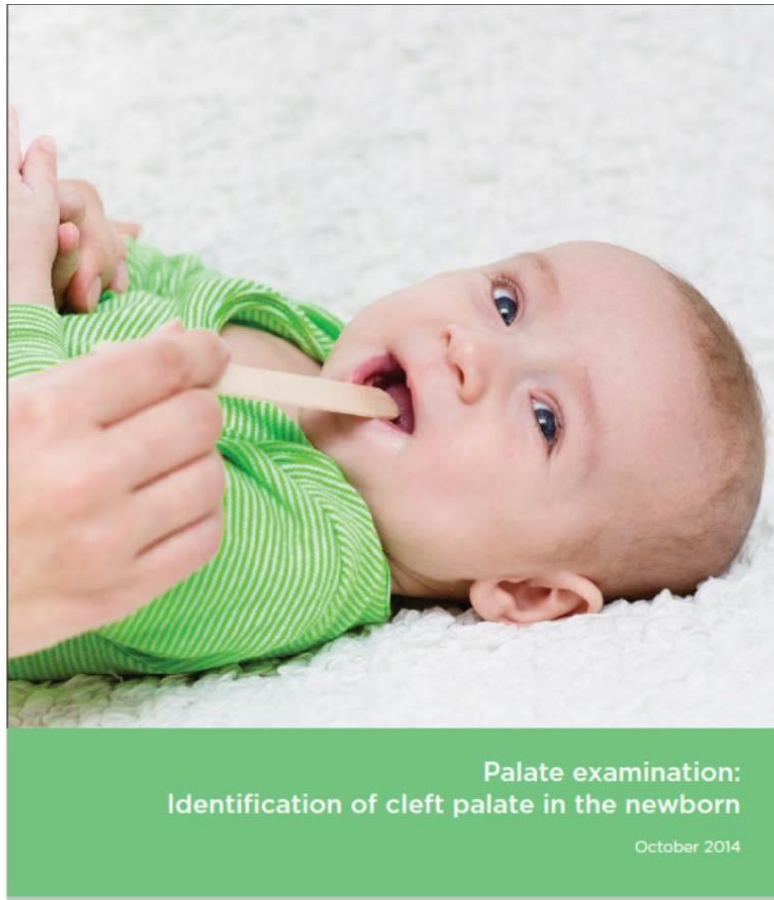
Cleft lip+/- palate more common in **boys**

10% CL/P associated syndrome or other anomaly

CP commoner in **Girls**

**50%** CP associated syndrome or other anomaly





British Association of Perinatal Medicine  
Cleft Lip and Palate Association  
Royal College of General Practitioners  
Royal College of Midwives  
Royal College of Paediatrics and Child Health  
The Craniofacial Society of Great Britain and Ireland

**RCPCH**  
Royal College of  
**Paediatrics and Child Health**  
*Leading the way in Children's Health*

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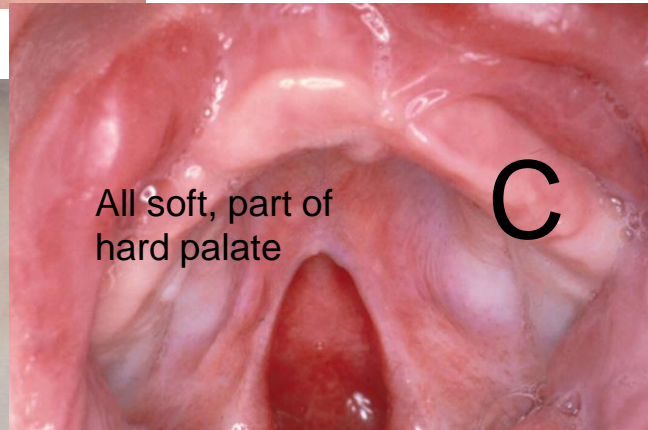
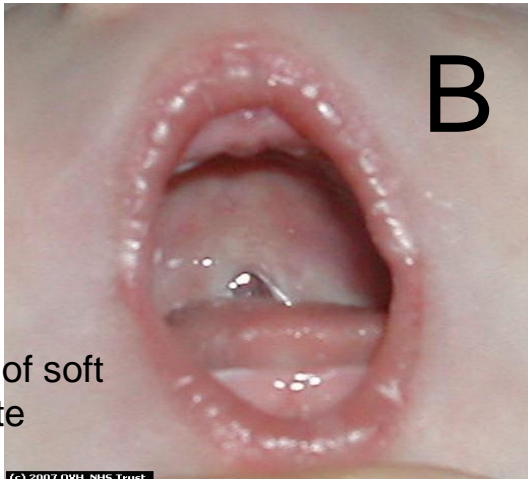
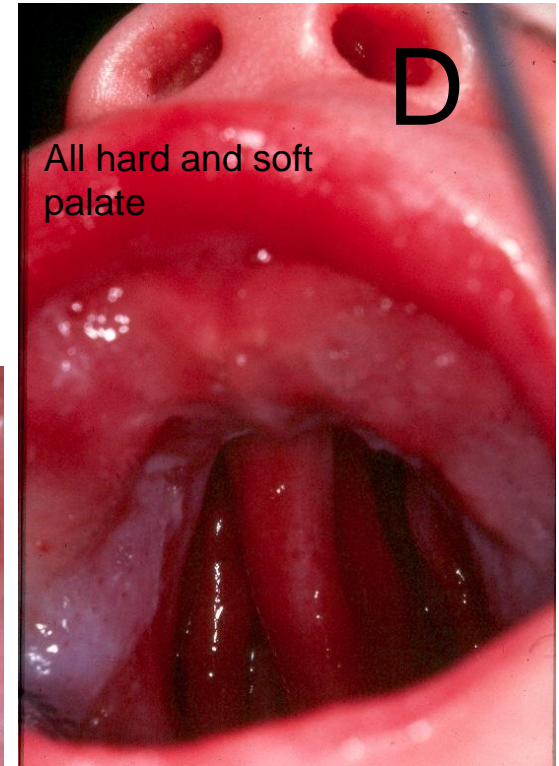
# Best practise recommendations

1. Healthcare professionals should examine a baby's hard and soft palate as part of the full newborn physical examination and record this in the child health record.
2. Examination of the baby's palate should be carried out by visual inspection.
3. A torch and method of depressing the tongue should be used to visualise the whole palate.
4. Parents should be informed if the whole palate (including the full length of the soft palate) has not been visualised during the newborn examination.
5. If the whole palate is not able to be visually inspected at first attempt then a further attempt at visual examination should be made within 24 hours.
6. Trusts should provide training on the correct method of visual inspection of the palate to all healthcare professionals required to carry out the newborn examination





## 2. Cleft Palates



(c) 2007 QVH NHS Trust







# Effects of Cleft for the Infant

Breathing (SLUMBRS research)

Feeding

Hearing

Surgery

Babbling/Speech



Cleft Lip with or without Palate  
10% associated anomalies



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# Beginnings:- Antenatal

3D Scan at 28 weeks

- 50% clefts involve lip
- Clefts of lip increasingly being identified at 20 week anomaly scan (Foetal Anomaly Screening Programme guidelines).





# Following Antenatal Referral

- CNS contact within 24hours of referral/diagnosis
- Home visit by CNS arranged
- Accompany to FMU if required
- Counselling and Information



## Following Referral (2)

- Offer of opportunity to meet extended team
- Meet other parents
- Attend antenatal group
- Letter/contact with Primary Care Team
- Free private 4D bonding scan options



# CNS care in pregnancy

- Help adjust to diagnosis and re-establish control of pregnancy.
- Home visits by CNS to plan early neonatal care
- Supports maternal choice of planned feeding
- Management plan agreed with parents and sent to DGH of delivery
- Feeding equipment and electric pump provided to parents





# FMU:-Further investigations

Additional anomalies/syndromes more commonly associated with:

- Isolated cleft palate (not identified on scan)
- Bilateral cleft Lip & palate
- Family history of syndrome
- Invasive testing should be offered only where other markers are identified

(Gillham 2009).

- Genetic consultation may be appropriate
- Termination may be considered if other serious markers/chromosome anomalies present.





# Pierre Robin Sequence

- Cleft palate
- Micrognathia
- Glossoptosis
- Upper airway obstruction



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# Pierre Robin Sequence



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# Management

## MILD OBSTRUCTION

Positioning with feeding support

## MODERATE OBSTRUCTION

Positioning with NG/Limited oral feeding

## MORE SEVERE OBSTRUCTION

Nasopharyngeal airway

Non nutritive stimulation/NG feeding

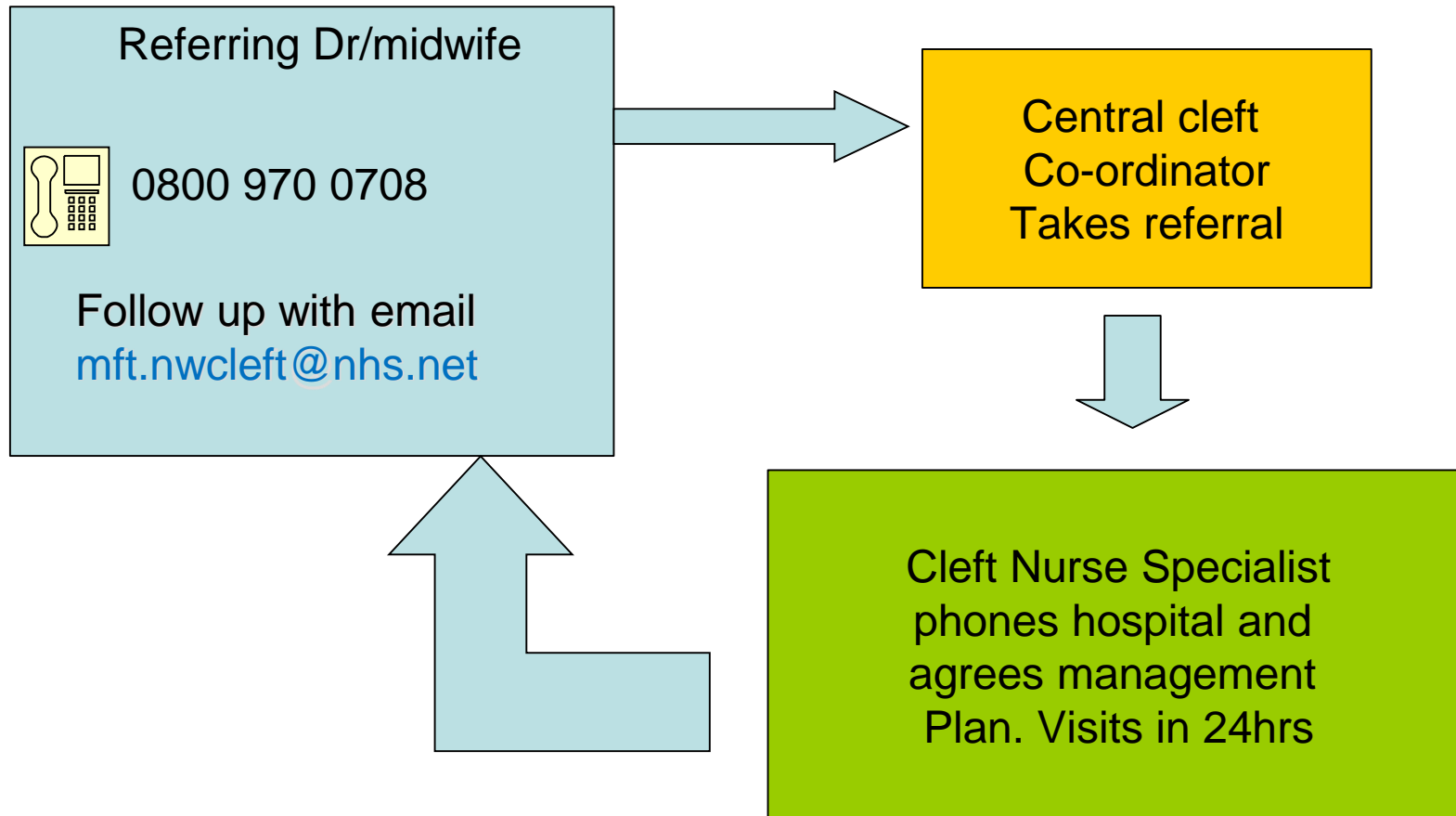




# Early management from birth

- Refer as soon as possible
- Cleft type, gestation, other medical conditions determine feeding management

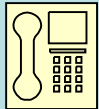
## Referral Process (Mon –Fri 9.00-17.00)



# Referral Process out of hrs

Referring Dr/Midwife

5pm – 9pm, 7am – 9am,  
week-ends & Bank Holidays



0800 970 0708

Follow up with email

[mft.nwcleft@nhs.net](mailto:mft.nwcleft@nhs.net)

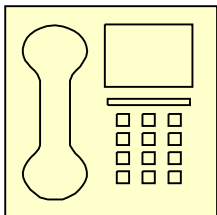
1st

Ansaphone  
Gives on call  
Nurse  
number

2nd

Cleft Nurse Specialist  
speaks to hospital and  
agrees management  
plan. Normally baby visited  
in 24hrs of referral.

# Referring Clefts



0800 970 0708



New referrals 0800 970 0708

Follow up with email  
[mft.nwcleft@nhs.net](mailto:mft.nwcleft@nhs.net)

CLEFT LIP AND PALATE NETWORK  
North West England, Isle of Man and North Wales

**NHS**

Please fax to 0161 701 9093. If you have any queries, please phone 0800 970 0708

**ANTENATAL / NEW BABY REFERRAL FORM**

DATE OF REFERRAL		NAME OF HOSPITAL (and Trust)	
MUM'S NAME			
CHILD'S NAME			
DOB	EDD	<input type="checkbox"/> MALE or <input type="checkbox"/> FEMALE	
CLEFT TYPE			
OTHER CONDITIONS KNOWN AT TIME OF REFERRAL			
HOME ADDRESS			
HOME CONTACT TELEPHONE NUMBER			
GP NAME			
GP ADDRESS			
GP TELEPHONE NUMBER			
BABY'S LOCATION AT TIME OF REFERRAL			
REFERRED BY:		DESIGNATION:	
NAME:			
ADDRESS FOR CORRESPONDENCE:			
SIGNATURE:			
REFERRING CLINICIAN'S CONTACT NUMBER			
PATIENT'S CONSULTANT PAEDIATRICIAN:			
FOR CLEFT OFFICE USE			
CLEFT SURGEON INITIALS:	CLINICAL NURSE SPECIALIST:	ANTENATAL REFERRAL YES IS NO IS	

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**CLEFT LIP AND PALATE NETWORK**  
North West England, Isle of Man and North Wales

Please fax to 0161 701 9093 or email [mt.nwcleft@nhs.net](mailto:mt.nwcleft@nhs.net) **FOLLOWING** your initial referral telephone call to 0800 970 07 08.

Referrals should not be faxed or emailed without having already TELEPHONED the referral though to the Cleft Network.

**ANTENATAL / NEW BABY REFERRAL FORM**

<b>DATE OF REFERRAL</b>		<b>NAME OF HOSPITAL (and Trust)</b>	
<b>MUM'S NAME</b>			
<b>CHILD'S NAME and NHS number</b>			
<b>DOB</b>	<b>EDD</b>	<input type="checkbox"/> <b>MALE</b> or <input type="checkbox"/> <b>FEMALE</b>	
<b>CLEFT TYPE</b>			
<b>OTHER CONDITIONS KNOWN AT TIME OF REFERRAL</b>			
<b>HOME ADDRESS</b>			
<b>HOME/CONTACT TELEPHONE NUMBER</b>			
<b>GP NAME</b>			
<b>GP ADDRESS</b>			
<b>GP TELEPHONE NUMBER</b>			
<b>BABY'S LOCATION AT TIME OF REFERRAL</b>			
<b>REFERRED BY:</b>		<b>DESIGNATION:</b>	
<b>NAME:</b>			
<b>REFERRING CLINICIAN'S CONTACT NUMBER</b>			
<b>PATIENT'S CONSULTANT PAEDIATRICIAN:</b>			
FOR CLEFT OFFICE USE			
<b>CLEFT SURGEON INITIALS:</b>	<b>CLINICAL NURSE SPECIALIST:</b>	<b>ANTENATAL REFERRAL YES <input type="checkbox"/> NO <input type="checkbox"/></b>	

October 2021





# Genetics

- Available to all parents & children
- Referral where other anomalies
- Clinical and chromosome assessment
- Advise on further investigations
- Chromosome investigations only necessary where other markers
- Cleft collective study





# CLEFT IN NORTH WALES

- 6000 livebirths
- Incidence of all clefts variable year on year and across 3 hospitals
- UK incidence 1/650-700 livebirths
- Network average 1/650 livebirths





# North Wales INCIDENCE BY YEAR

2017 – 19 clefts 1/333

2018 – 17 clefts 1/352

2019 – 8 clefts 1/750

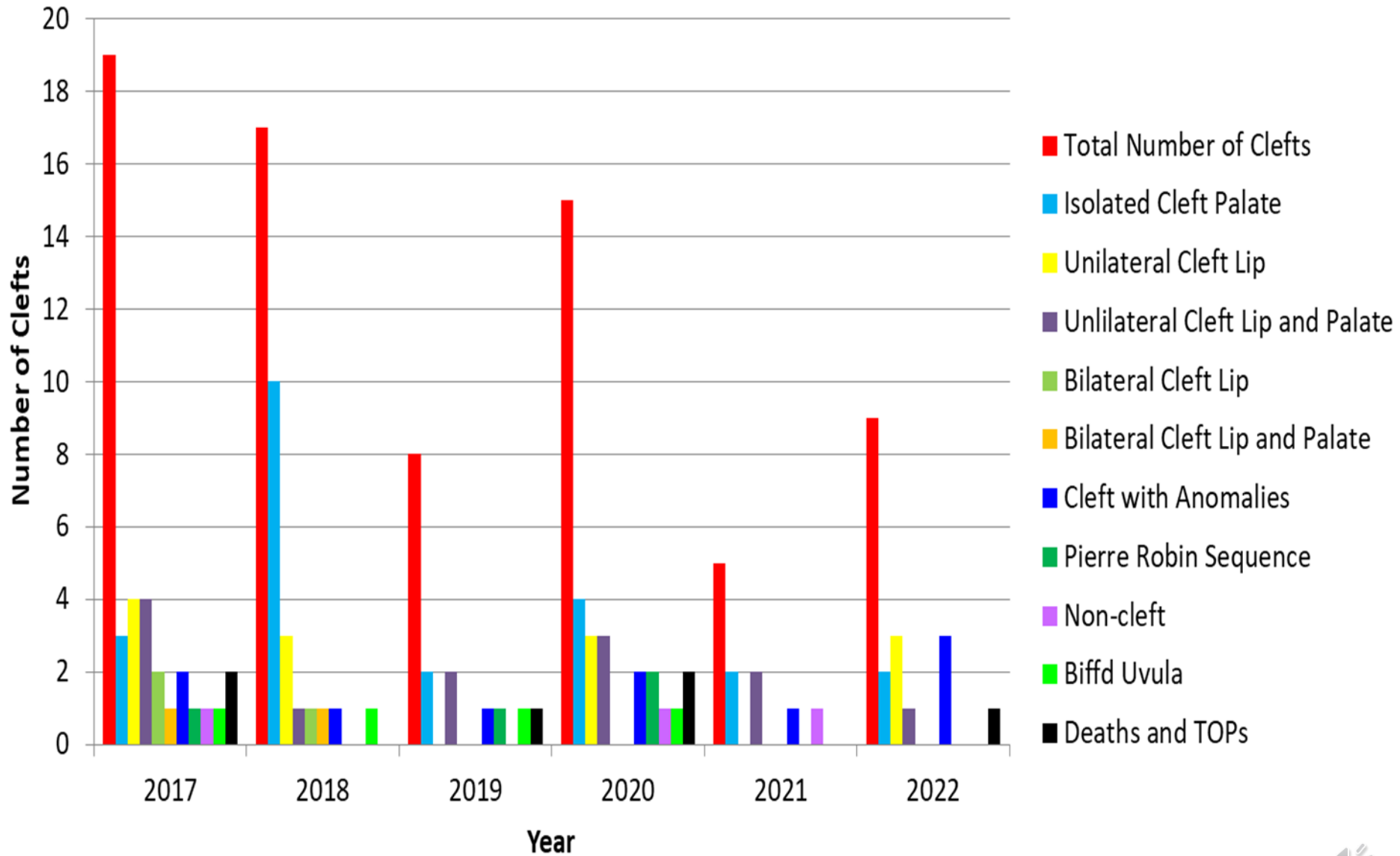
2020 – 15 clefts 1/400

2021 – 5 clefts 1/1200

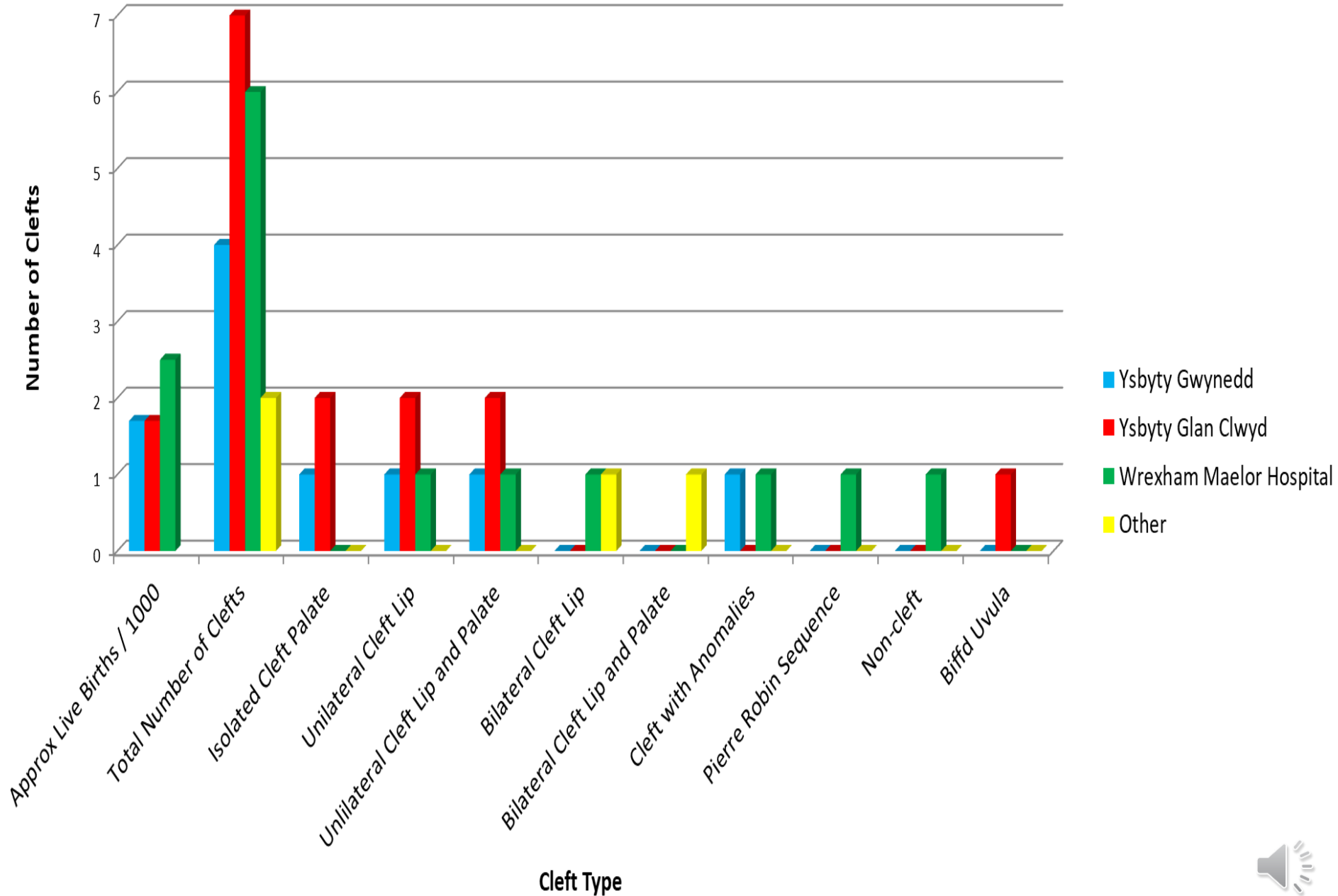
2022 (to date) – 9 clefts (1/666)



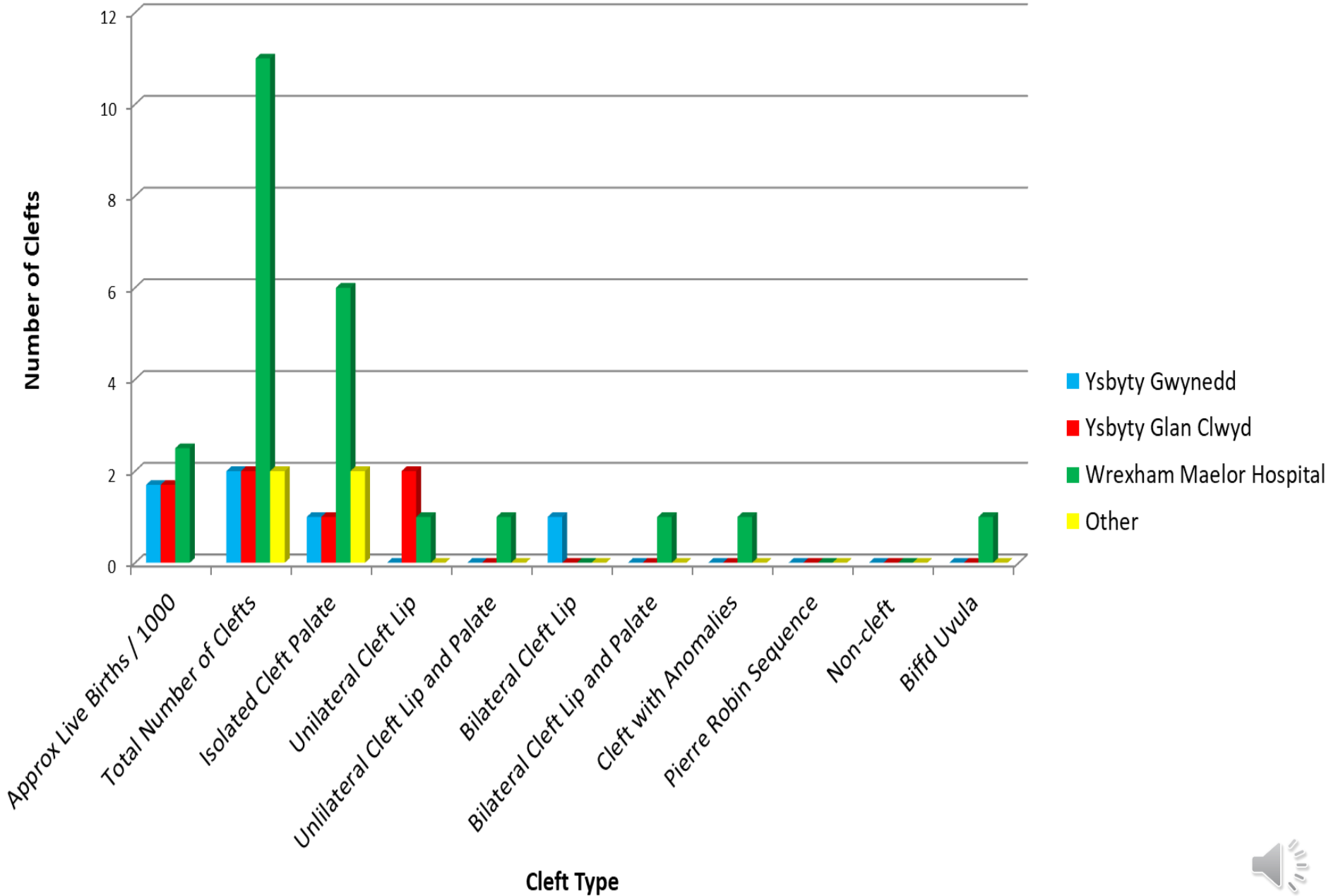
# Yearly Cleft Data



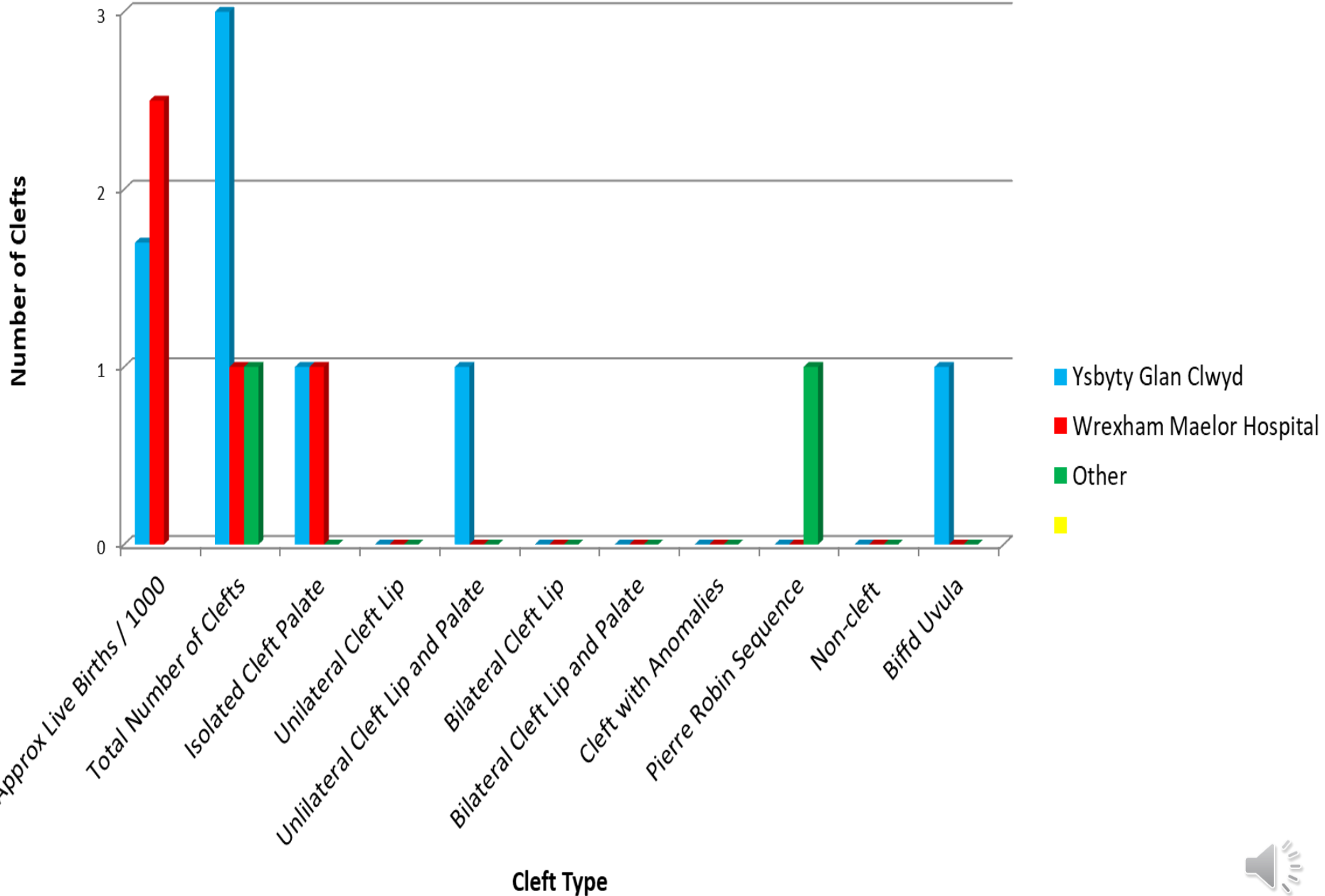
# Cleft Type and Number per NW Hospital 2017



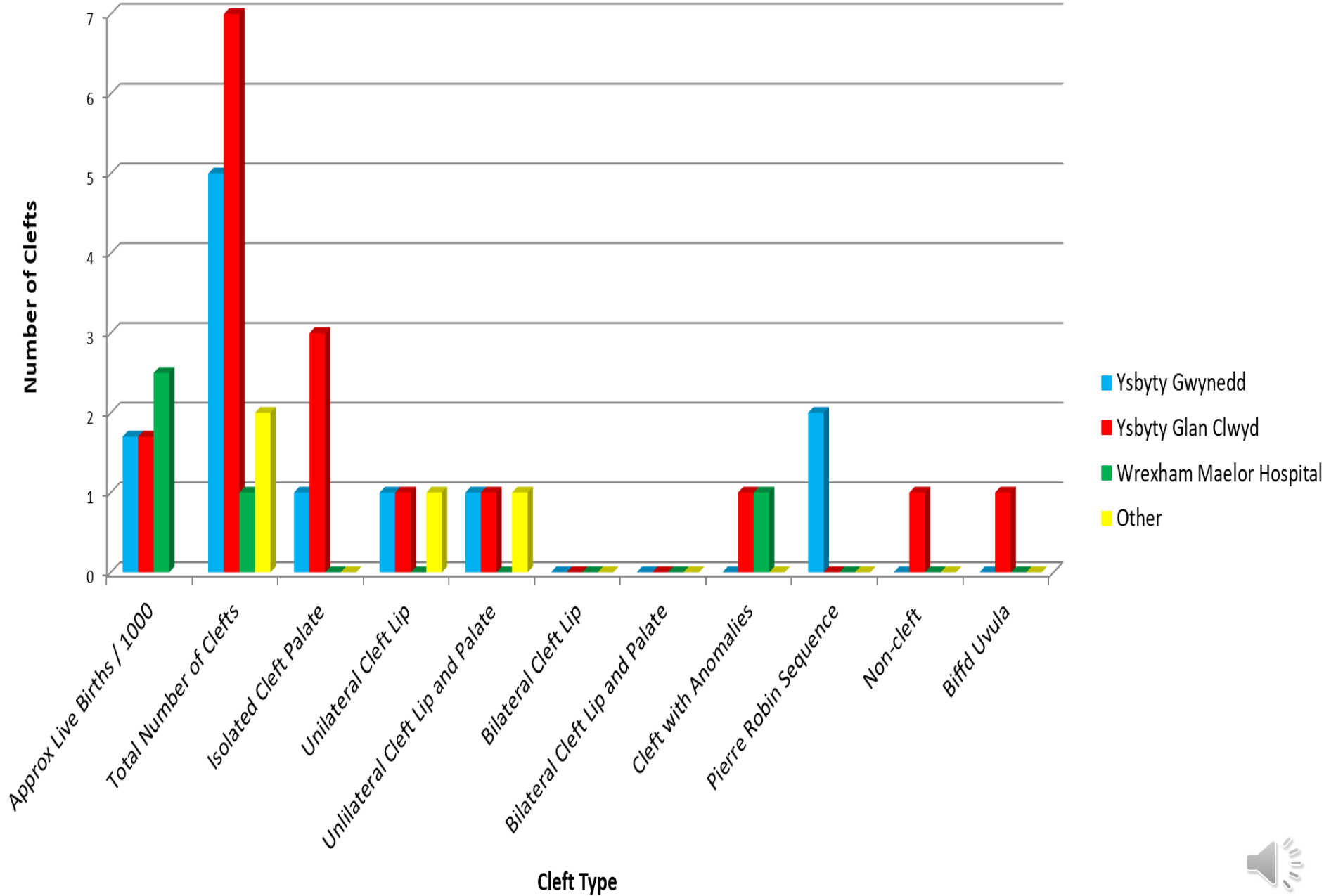
# Cleft Type and Number per NW Hospital 2018



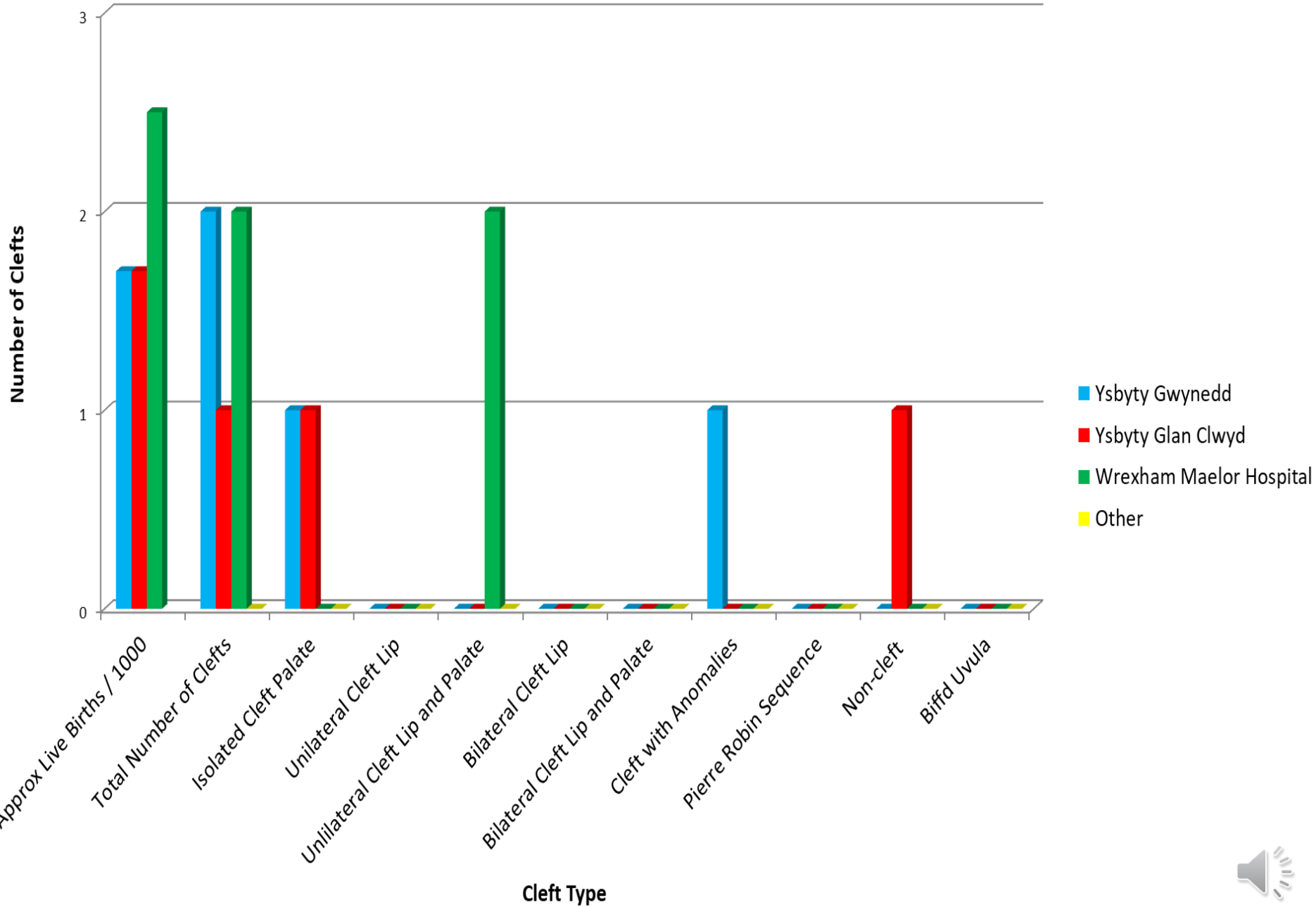
# Cleft Type and Number per NW Hospital 2019



# Cleft Type and Number per NW Hospital 2020

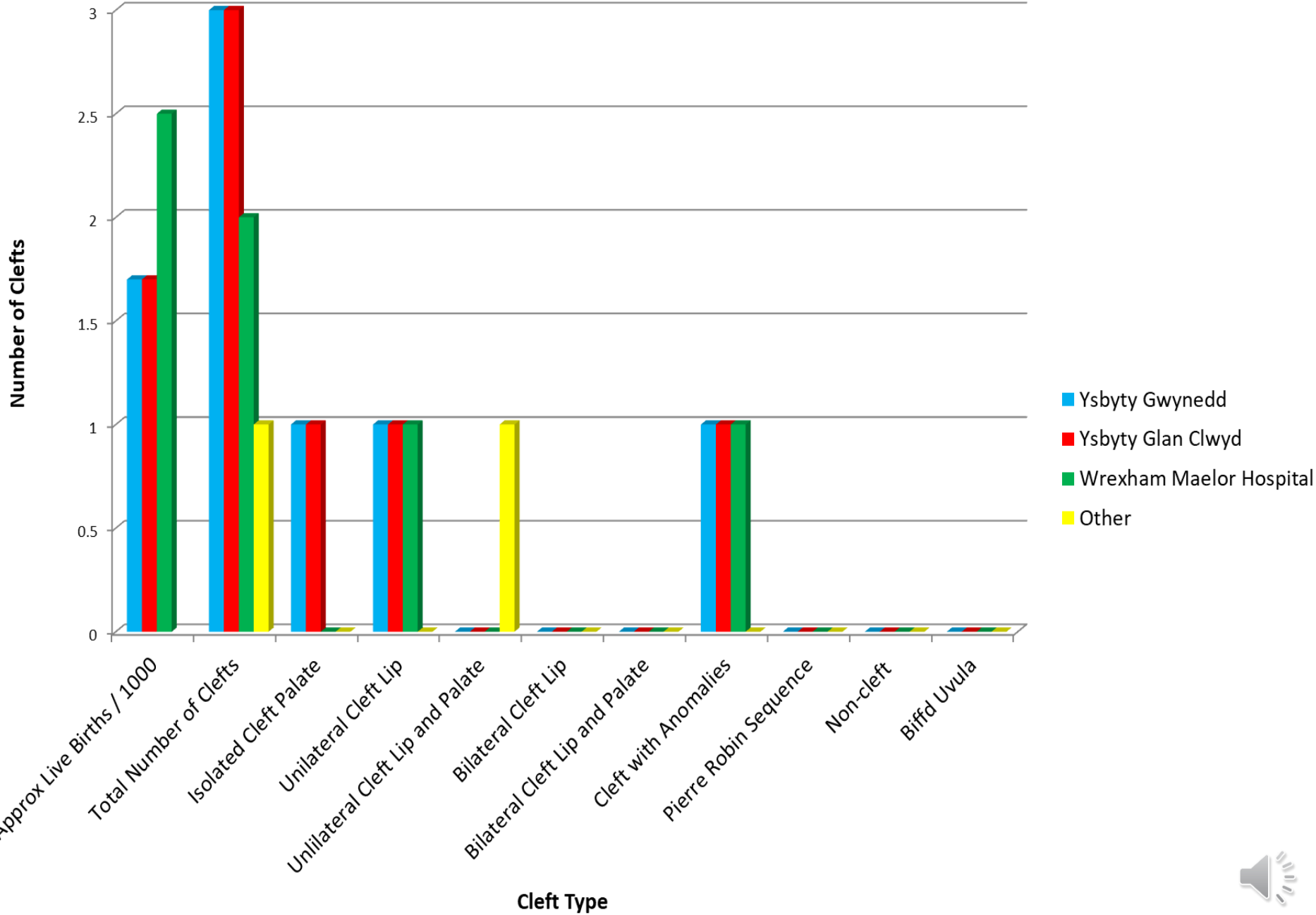


# Cleft Type and Number per NW Hospital 2021





# Cleft Type and Number Per NW Hospital 2022 To Date



# Jess and Toby's Story





# SUMMARY

- Cleft Service and role of MDT
- Best Practice Guidelines re detection of cleft palate
- Early referral to Nurse Specialist

0800 9700708

[mft.nwcleft@nhs.net](mailto:mft.nwcleft@nhs.net)





# THANK YOU

KATY STEPHENSON

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07855134498

