Paper prepared for presentation to the Citizens Assembly at the request of Justice Mary Laffoy, dealing with a neonatologist's perspective of babies born with severe fetal anomalies.

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Introduction

- Many babies with congenital anomalies born each year in Ireland
- Majority survive
- Some are complex
- With anatomy scanning and more advanced testing most are diagnosed and parents counselled
- With advances in paediatric palliative care the management of those that don’t survive has improved

Main Indications for Admission to the Rotunda Neonatal Unit 2015 (n-1,311)

RESPIRATORY SYMPTOMATOLOGY	523	
PREMATURITY < 37 WEEKS	357	
JAUNDICE	360	
LOW BIRTH WEIGHT < 2.5Kg	446	
HYPOGLYCAEMIA	241	
CONGENITAL ABNORMALITIES	**240**	
SUSPECTED SEPSIS	40	
NEONATAL ABSTINENCE SYNDROME	28	
SEIZURES	8	
HIE	29	
GASTRO-INTESTINAL SYMPTOMS	15	
SOCIAL	5	
DEHYDRATION	16	

*Some Infants are assigned more than one reason for admission

NNTP Transports 2014 & 2015
Primary Clinical Reason for transfer

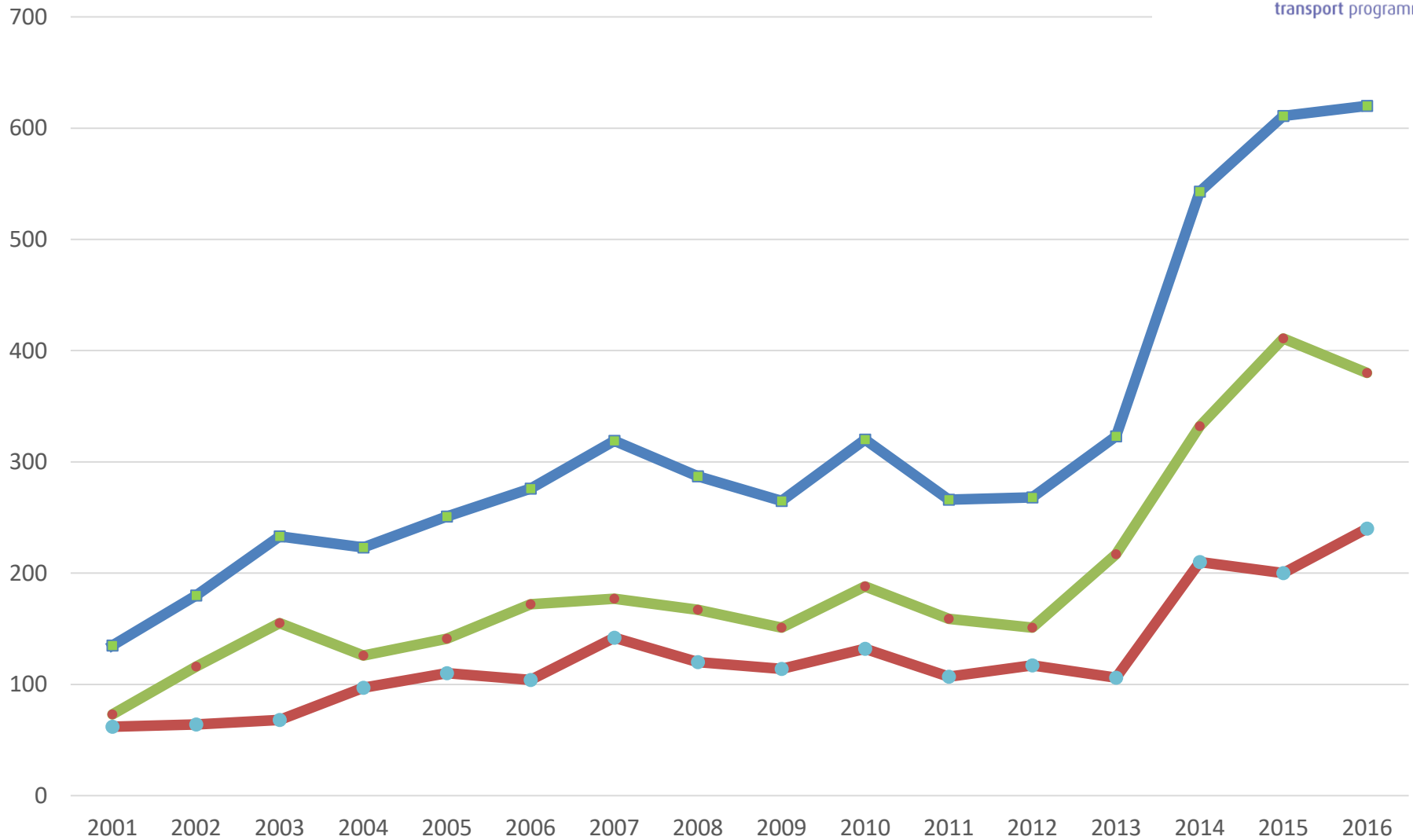
national neonatal transport programme

	Medical	Surgical	Cardiac	Neurological
2014	237	130	124	52
2015	289	145	133	44
%	45.6%	23.8%	22.3%	8.3%

Over 600 babies transferred 2015; 52% (322) had congenital anomalies

NNTP Transports 2001-2016, n= 5120

national neonatal transport programme



A Foran 7th Jan 2017

Case 1

- Jane Kelly aged 37 first pregnancy
- Anomaly scan at 22 weeks ? Edwards' syndrome
- Amniocentesis confirms T 18
- Counselled: outcome and survival data are shared with the parents
- Clear care plan is put in place.
- Baby David is born at 37 weeks weighing 2kg (4lb 6oz).
- He is nursed on the ward with parents
- Specialist imprints of his foot and hand prints are taken
- He passes away 12 hours after delivery
- Bereavement follow up and counselling is arranged by the bereavement midwifery team

Case 2

- Jane Kelly is a 28 year old lady expecting twins
- At the 20 week anomaly scan 2nd twin has a congenital heart defect that will require complex surgery.
- Preterm labour at 27 weeks counselled re preterm and cardiac defect.
- The minimum weight a baby can undergo this complex surgery is 2.5kg (5lb 8oz).
- A plan is put in place to monitor the affected twin after delivery
- Twins born at 27 weeks and 2 days
- Twin 1 Mary 1.1kg (2lb 6oz) and twin 2 John weighs 850g (1lb 13oz).
- John is immediately commenced on medication to keep his duct open (PDA) and high calorie intravenous nutrition (TPN) to maximise his growth

Case 2 cont….

- 3 weeks post-delivery the PDA starts to close, he weighs 1.1kg (2lb 6oz) and is significantly below any weight where surgery is technically possible.
- MDT counselling, care is redirected
- John is baptised, extended family visit and a memory box is made.
- He is transferred to a quieter section of the NICU. Photos are taken without any equipment and the parents dress him in clothes they have chosen. He dies peacefully in his mum's arms 40 minutes later

Case 3

- Jane Kelly is a 32 year old lady on her fourth pregnancy.
- Centre doesn't have fetal anomaly scanning available.
- Baby Mary born at 39 weeks, weighing 3.5kg (7lb 11.4oz).
- The baby has difficulty breathing at birth and is noted to have multiple congenital anomalies.
- The baby is transferred to Rotunda
- Then PICU in one of the Children's hospitals for further assessment
- Following over 2 weeks of intensive care it transpired that despite not having the typical facial appearance and low birth weight, Mary has Patau's syndrome and care is redirected. Mary dies peacefully in her father's arms some 20 minutes later.

Case 4

- Jane Kelly 42 year old lady expecting her first baby (5 X IVF).
- Non-invasive prenatal testing was normal yet concerns raised from the anomaly scans amniocentesis : normal karyotype and microarray results.
- Baby John was born at 38 weeks by elective section.
- He could not be intubated and alternative airway was inserted.
- Transferred to one of the Children's Hospital's for an emergency tracheostomy.
- Multiple operations over 12 months
- He had severe developmental delay, seizures and an inability to survive without intensive airway support.
- Following numerous MDT meetings with the parents, John was taken home with the support of the palliative care team and spent three weeks at home before passing away peacefully.

Conclusion

- Complex not always clear cut
- Antenatal anatomy scanning & other testing aids counselling and planning for delivery
- Not always conclusive
- Advances in palliative care and bereavement counselling has improved care for those that don’t survive

Thank You