PERINATAL PALLIATIVE CARE.FOUNDATION AND EXPERIENCES
Rome - DECEMBER 1° .2022 12°
WEBINAR (ZOOM PLATFORM 2:00- 5,00 (ROME TIME)

PROMOTING A CULTURE OF ACCOMPANIMENT THROUGH PPC

GIUSEPPE NOIA

PERINATAL HOSPICE
CENTER FOR PRENATAL AND POSTNATAL PALLIATIVE TREATMENTS
«S.MADRE TERESA DI CALCUTTA»
POLICLINICO GEMELLI
ROMA

PONTIFICIA ACADEMIA PRO VITA

Fondazione
Il Cuore in una Goccia

UNIVERSITÀ CATTOLICA del Sacro Cuore

Gemelli

Fondazione Policlinico Universitario Agostino Gemelli IRCCS
Università Cattolica del Sacro Cuore

Cultural connotation of pregnancy today in second quarter:

Obstacle course

Eugenic abortion after the third month in Italy
Law 194 (1978)

RATE 1981 ***0,5 %***

RATE 2013 ***4.2%***

RATE 2015 ***5.0 %***

RATE 2019 ***6.2%***

Italian Ministry of health

About 4000 eugenic abortions every year !

Science without consciousness can become the ruin of the spirit of humanity

Rabelais, 1534.

How do we use the science?

We must not be afraid of “Galileo”

but how we use “Galileo” (the science)

TRIBUTE TO A GREAT MASTER OF BIOETHICS:
CARDINAL ELIO SGRECCIA

Science without the lighthouse of ethics is a ship that gets stuck

The PRIMACY of bioethics

"You were born not to live as brutes but to follow virtu (ETHICS) and knowledge ! "

DANTE ALIGHIERI


Obstetric echography:
Is the best way
to terrify a pregnant
woman.
Informed consent must be based on scientifically
rigorous knowledge of natural hystory
of congenital anomalies
Filly J. Ultrasound Med. 2002

The loneliness and confusion of families facing pathological prenatal diagnosis

The shortcomings and gaps
that create suffering for families
facing prenatal frailness
and fuel the "waste" culture

Lack of:

MEDICAL SUPPORT

SUBTLE INDUCTION TO VOLONTARY ABORTION
(often even in absence of certain diagnosis)

or

LACK OF ASSISTENCE
in case of decision to carry on the pregnancy

CORRECT INFORMATIONS

- **RISK AMPLIFICATION**
- Incorrect or dated convinctions about pathologies
- Not aware of the NATURAL HISTORY of pathology

OTHER TIPES OF SUPPORT

LACK OF RECEPTION and understanding by physicians, family members and other figures, which increases the state of suffering of future parents.
LACK OF PSYCHOLOGICAL SUPPORT in the acceptance of the child's pathology or any loss.
LACK OF ECONOMIC SUPPORT: often heavy costs to treat your child sick.

REFERENCE POINTS

- Who am I addressing?
- Which specialist should I consult?
- What medical facilities are involved in my son's pathology?
- Are there any facilities in my area? Etc...

THE FETUSES «LOST CONSIDERED»

But who are incompatible children with the extrauterine life, improperly called "terminals"?

Who are the subjects on which the waste culture is affected, considered improperly "imperfect"?

THE PATHOLOGIES WHERE NATURAL HISTORY APPEARS IMPORTANT

1st Group ***INDUCED LIFE LIMITING CONDITIONS***

(by the lack of or incorrect knowledge of the natural history of prenatal pathology)

Cystic hygroma - infectious diseases (toxo, rubella, cmv) -
Genetic anomalies (trisomy 18- 21)

2nd Group ***INDUCED LIFE LIMITING CONDITIONS***

(from defensive medicine, risk amplification and intellectual sloth)

Severe tachyarrhythmias - severe fetal hydrops -severe rh incompatibilitibility - p-prom - spina bifida – hydrocephalus - severe low obstructive uropathy – megabladder - TTTS twin pregnancy – CCAM.

3rd Group ***REAL LIFE LIMITING CONDITIONS***

anencephaly –acrania - bilateral renal agenesis - early renal dysplasias - tanatophoric dwarfism – triploidies - trisomy 13-polymalform. syndromes

POST NATAL SURVIVAL OF SOME LIFE LIMITING CONDITIONS

Anomalie fetali severe	Prevalenza	Probabilità di vita alla nascita	Sopravvivenza media postnatale	Ad 1 settimana	Ad 1 anno	Sopravvivenza più lunga riportata
Agenesia renale	1.7/10.000	Non riportata	<24h	< 5%	Non riportata	13 mesi
Anencefalia	10/ 10.000	62-72%	Da <24h a 55 minuti	0-14%	7%	10 mesi / 2.5 anni
Displasia tanatofora	0.4/10.000	Non riportata	Non riportata	Non riportata	Non riportata	5 anni / 9 anni
Trisomia 18	2.6/10.000	48-51%	14 giorni	35-65%	14-19%	27 anni/ 30 anni/ 50 anni
Trisomia 13	1.2/10.000	28-46%	10 giorni	45-57%	14-21%	19 anni/ 27 anni
Oloprosencefalia	0.5/10.000	Non riportata	4-5 mesi	71%	47%	6 anni/ 11/13/ 19 anni

Wilkinson D. , de Crespigny L. , Xafis V. Ethical language and decision-making for prenatally diagnosed lethal malformations. Semin Fetal Neonatal Med 2014; 19: 306-311.

Pregnancy continuation and organizational religious activity following of prenatal diagnosis of a lethal defect are associated with improved psychological outcome

HEIDI COPE ET AL
PRENATAL DIAGNOSIS 2015, 35 761-768

158 WOMEN AND 109 MEN WHO HAVE LOST A PREGNANCY WITH ANENCEPHALY

- PERINATAL GRIEF SCALE
- IMPACT OF EVENT SCALE
- REVISED AND BECK DEPRESSION INVENTORY -II

RESULTS

CONTINUE PREGNANCY

Versus

TERMINATE PREGNANCY

DESPAIR	*P = 0.02*
AVOIDANCE	*P = 0.008*
DEPRESSION	*P = 0.04*

Greater

IN THOSE WHO VOLUNTARILY MISCARRIES

HOW CAN PRENATAL SCIENCE PROTECT NASCENT LIFE AND HIS FRAGILITY?

SCIENTIFIC, ETHICAL AND CULTURAL ANSWER

THE PERINATAL HOSPICE

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CENTER FOR PRE-NATAL AND POSTNATAL PALLIATIVE CARE
S. MADRE TERESA DI CALCUTTA
«A. GEMELLI» – UNIVERSITY POLYCLINIC FOUNDATION
ROME

SPECIALISED OPERATIVE UNIT, located in hospital structures (with a birth point), equipped with a **MULTIDISCIPLINARY TEAM** to provide specialised assistance to families who have to face prenatal diagnoses of **SEVERE PATHOLOGIES AND MALFORMATIONS** often life limiting conditions.

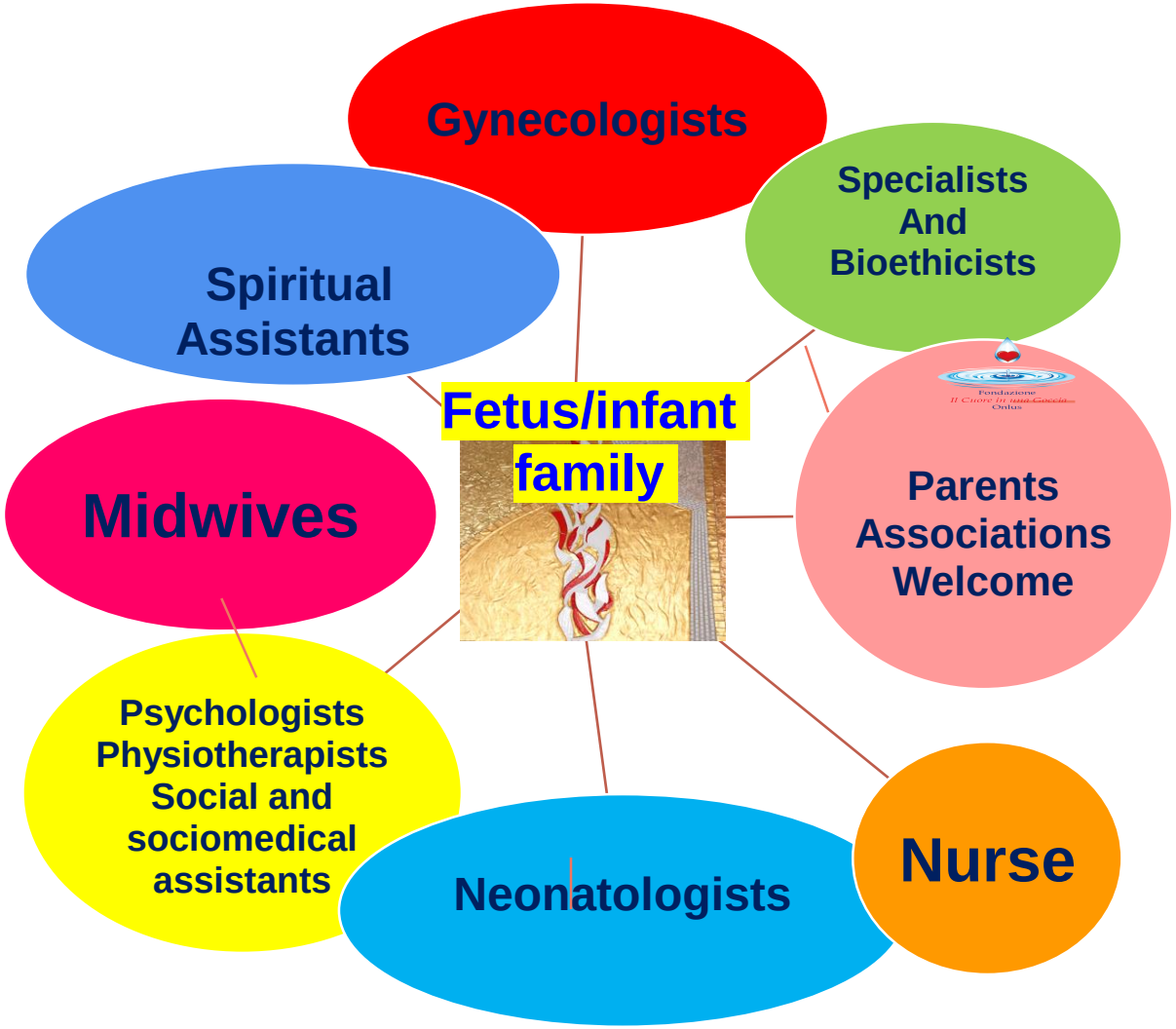
REFERENCE POINT FOR FAMILIES IMPACTING WITH THE PATHOLOGICAL EVENT

July 2015
First Perinatal Hospice in Italy

Fondazione
Il Cuore in una Goccia
Onlus

Perinatal Hospice
Center for Prenatal and Postnatal PalliativeTreatments
S.Madre Teresa di Calcutta
Policlinico Gemelli – Roma

PERINATAL HOSPICE AND NEONATAL PALLIATIVE CARE



- **Pediatric Cardiologist**
  Pediatric Cardiac Surgeon
- **Pediatric Neurosurgeon**
- **Pediatric Surgeon**
- **Genetician**
- **Pediatric dysmorphologist-rare diseases**
- **Pediatric Nephrologist**
- **Pediatric Neurologist**
- **Pediatric Gastroenterologist**

PERINATAL HOSPICE TEAM – NEONATAL PALLIATIVE CARE

- ***Transdisciplinary and interdisciplinary diagnostic-clinical and therapeutic approach***

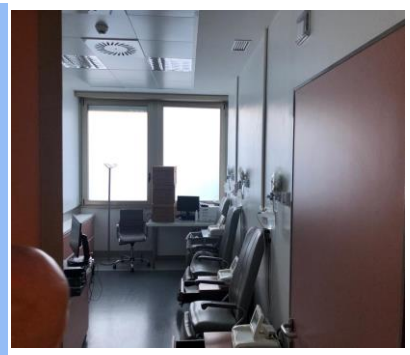
  Inter-professional team work
- ***Team-family communication***

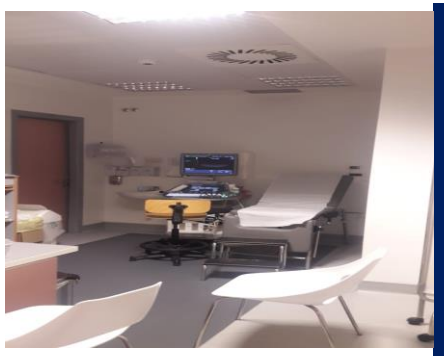
WHAT IS DONE IN THE PERINATAL HOSPICE

- Counselling and study of prenatal pathologies *(NATURAL HISTORY)*
- Medical, psychological and human care for pathological pregnancies
- Invasive and not invasive prenatal therapies;
- Analgesia for fetal pain in case of invasive procedures that cross fetal body (*PRENATAL PALLIATIVE CARE)*
- Welcoming and accompaniment of children with life limiting conditions and their families soon after the severe prenatal diagnosis (*INCLUSION IN PATH ALREADY IN THE PRENATAL PHASE)*
- Comfort care and *POST-NATAL PALLIATIVE CARE*
- "SHARED DOCUMENTS"

SHARED PATH

Family Arrival at Hospice





Shared document

Childbirth and newborn

Multispecialty fetal problem reception and evaluation

Sharing care proposals with parents(childbirth/postpartum care)

Accompanying pregnancy, gynecological interventions, psychological support, courses of childbirth preparation

Fondazione
Il Cuore in una Goccia
Onlus

Perinatal Palliative Care -Perinatal Hospice

The Clinical Ethics Consultancy (CEC) and the Shared Document (SD) of Ethical Guidance, are tools that allow the planning of care and assistance to the patient in a shared way.

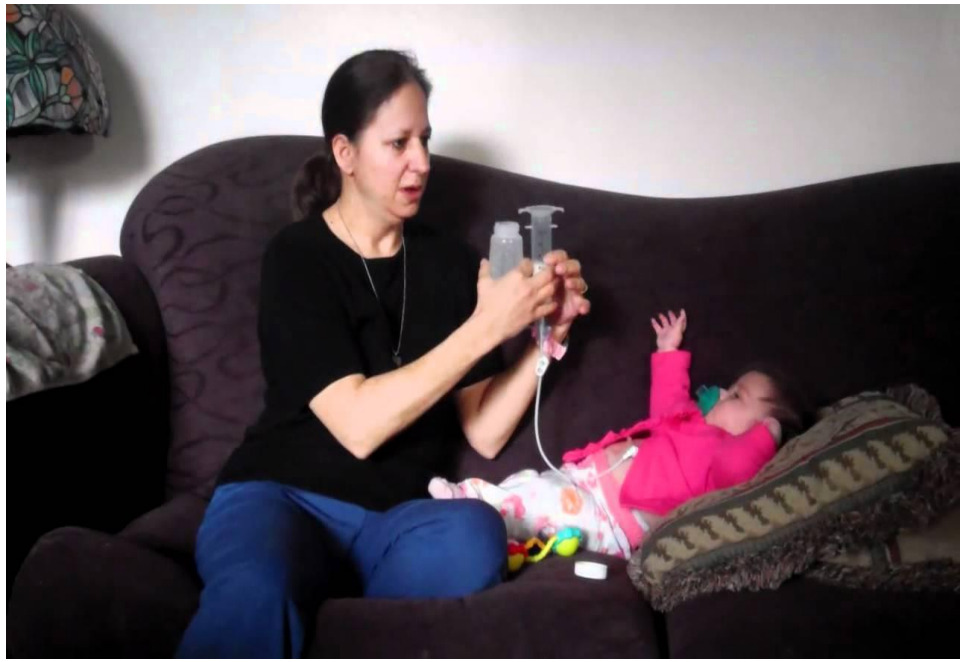
DIFFERENCES BETWEEN PERINATAL HOSPICE AND HOSPICE OF ADULTS

- **The planning of care in the hospice of adults is obliged to a path that is defined by the terminal pathology**
- **The planning of the Perinatal Hospice, on the other hand, can follow unexpected evolutions due to therapeutic and/or palliative interventions that can change the natural history of pathology**
- **The care of the hospice of adults involves unfortunately only projects that impact with suffering and death while the**

PERINATAL HOSPICE IMPACTS WITH PLANNING OF HOPE, LIFE AND CONCRETE RESULTS WITH BABY IN ARMS

«Il mantenimento del legame affettivo tra genitori e figlio è parte integrante del processo di cura. Il rapporto di accudimento e di accompagnamento genitore-bambino va favorito con tutti gli strumenti necessari e costituisce parte fondamentale della cura, anche per le patologie non guaribili e le situazioni ad evoluzione terminale.»

«***Samaritanus Bonus»***



Disability, despite being a social problem, remains almost exclusively the responsibility of families.

THE FEAR THAT OFTEN LEADS TO EUGENIC ABORTION IS PRECISELY CONNECTED WITH THE ABSENCE OF RELATIONSHIPS, ESPECIALLY SOCIAL ONES, BEING LEFT ALONE.

Paths open up with an uncertain future, livability is always at risk, but we live day by day.

THE PERINATAL HOSPICE

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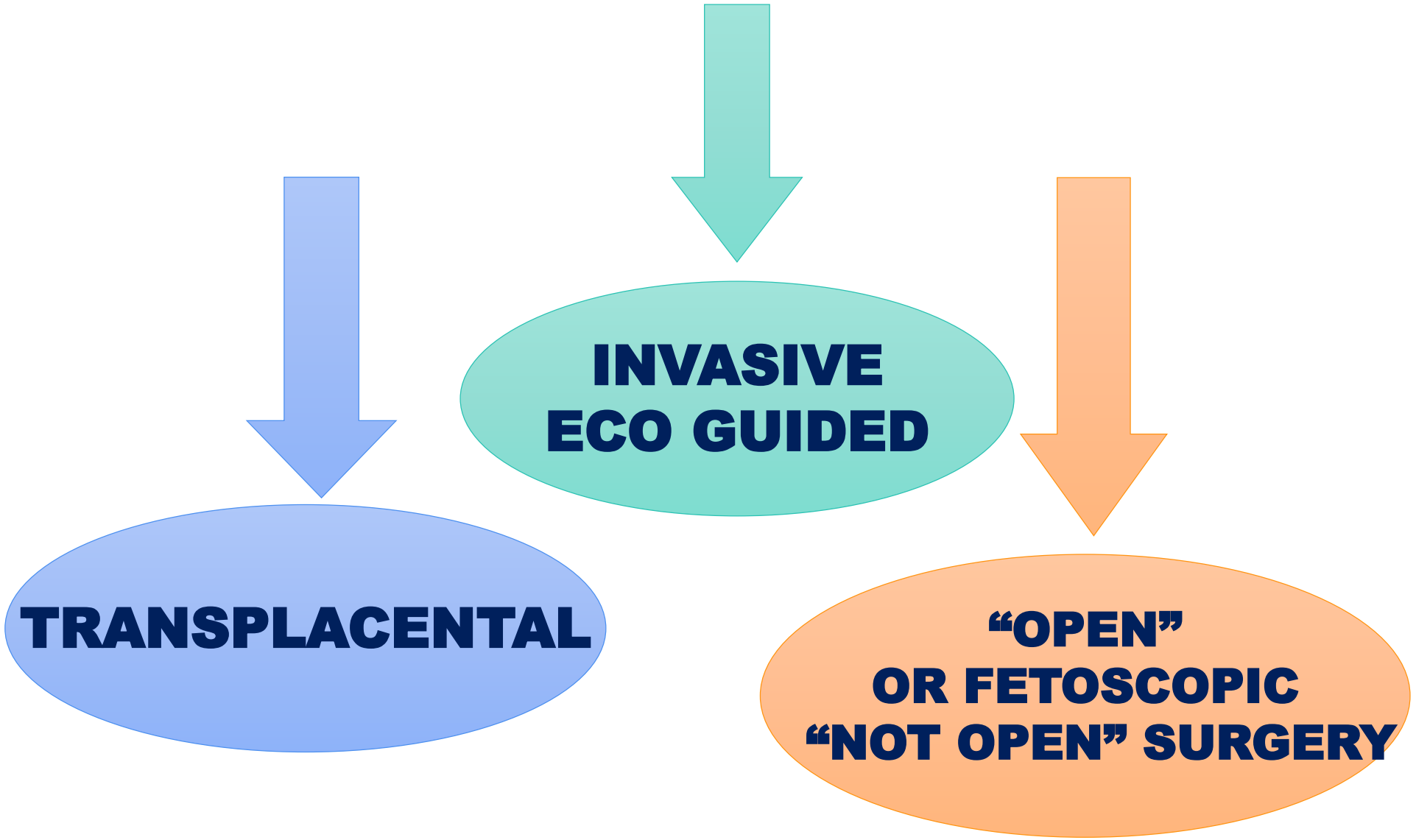
FETAL INTERVENTIONS
(PALLIATIVE TREATMENTS AND PROPER INVASIVE THERAPIES)

- **Amnioreduction (Polyhydramnios)**
- **Amnioinfusion (Oligohydramnios)**
- **Auto-amnioinfusion, Amnio-Exchange**
- **Cordocentesis and IUFT (intravascular and intra-peritoneal intrauterine transfusion for fetal anemia)**
- **Paracentesis (Ascites) – Thoracentesis (Hydrothorax)**
- **Cystocentesis – Pielocentesis-Shunt placement**
- **Fetal Analgesia – Fetal curarization**
- **Digitalization (Fetal heart failure)**
- **Administration of corticosteroids (RDS prevention)**

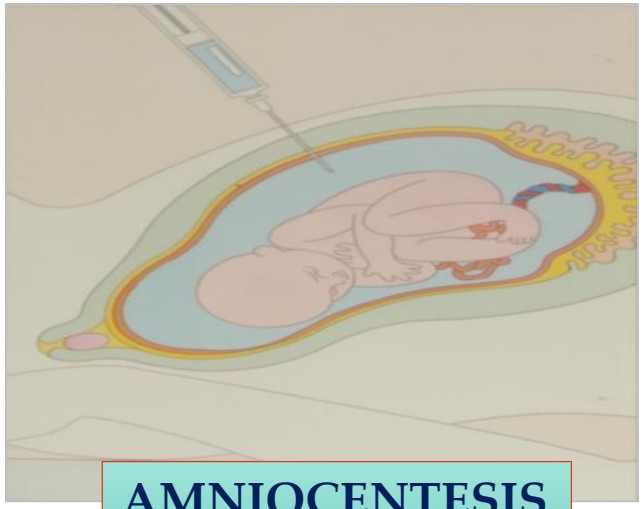
FETAL THERAPY



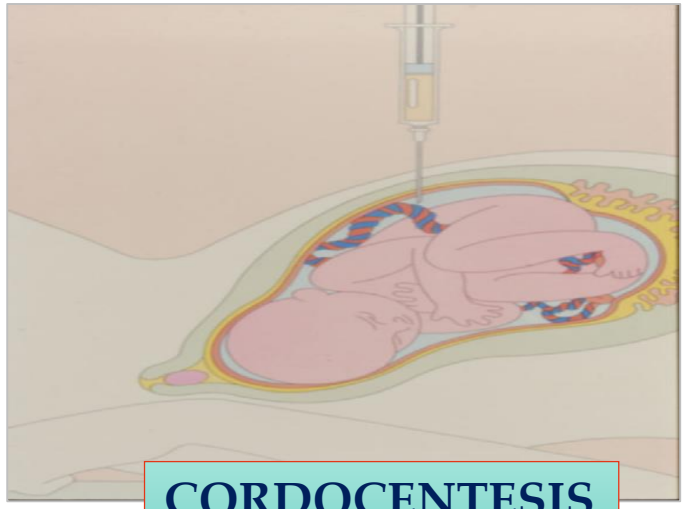
OUR EXPERIENCE (6 CASES) OF TRANSPLACENTAL THERAPY

CASE	WEEK	PRENATAL DIAGNOSIS	TRANSPLACENTAL THERAPY	OUTCOME
1	36	EXTRASYSTOLES TACHYCARDIA PAROXYSMAL (250 B.P.M.)	DIGOXIN 0.250 MG VERAPAMILE 160 MG CARDIOVERSION AFTER 7 DAYS	TC, 37 ES, 3.180 GR INTERMITTENT ARITHMIA DIGOXIN UNTIL 3rd MONTH BORN ALIVE
2	32 →	SEVERE HYDROPS TACHYCARDIA (200 B.P.M.)	DIGOXIN 0.250 MG VERAPAMILE 160 MG CARDIOVERSION AFTER 10 DAYS	TC, 34 ES, 2.540 GR MEDIUM ENTITY NEONATAL PARACENTESIS DIGOXIN TILL 1 YEAR BORN ALIVE
3	30 →	SEVERE HYDROPS TACHYCARDIA (240 B.P.M.) POLIAMNIOS	DIGOXIN 0.500 MG VERAPAMILE 320 MG CARDIOVERSION AFTER 15 DAYS	TC, 34 ES, 2.660 GR MEDIUM ENTITY NEONATAL PARACENTESIS DIGOXIN UNTIL 8TH MONTH BORN ALIVE
4	33 →	MODERATE HYDROPS TACHYCARDY (230 B.P.M.) AND SYTE OF HYDROPS	DIGOXIN 0.500 MG VERAPAMILE 80 MG CARDIOVERSION AFTER 12 DAYS	TC, 39 ES, 3.620 GR NO NEED FOR THERAPY BORN ALIVE
5	32	TACHYCARDY (210-240 B.P.M.) WITH ARITHMIA E ABSENCE OF HYDROPS	DIGOXIN 0.500 MG CARDIOVERSION AFTER 15 DAYS	SPONTANEOUS PART, 39ES, 2,650 GR, NO NEED FOR THERAPY BORN ALIVE
6	35 →	SEVERE HYDROPS TACHYCARDY (250 B.P.M.)	IDEM	BORN ALIVE

FETAL THERAPY



AMNIOCENTESIS



CORDOCENTESIS

INVASIVE ECO GUIDED:

approaches that

DO NOT CROSS

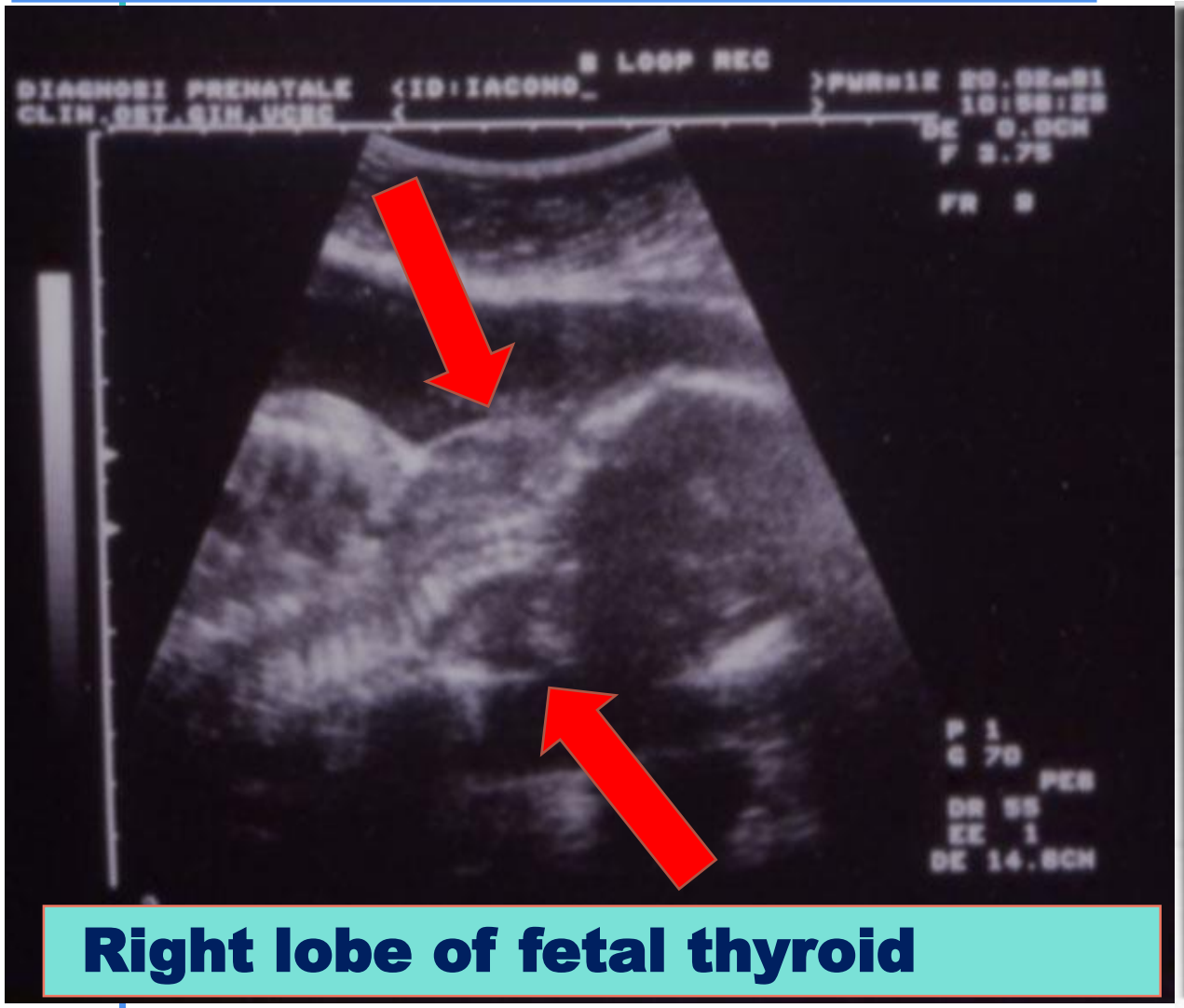
the fetal body

INTRAMNIOTIC APPROACH

Ecoguided prenatal invasive amnioinfusion of thyroxin complementary to maternal therapy for fetal goiter

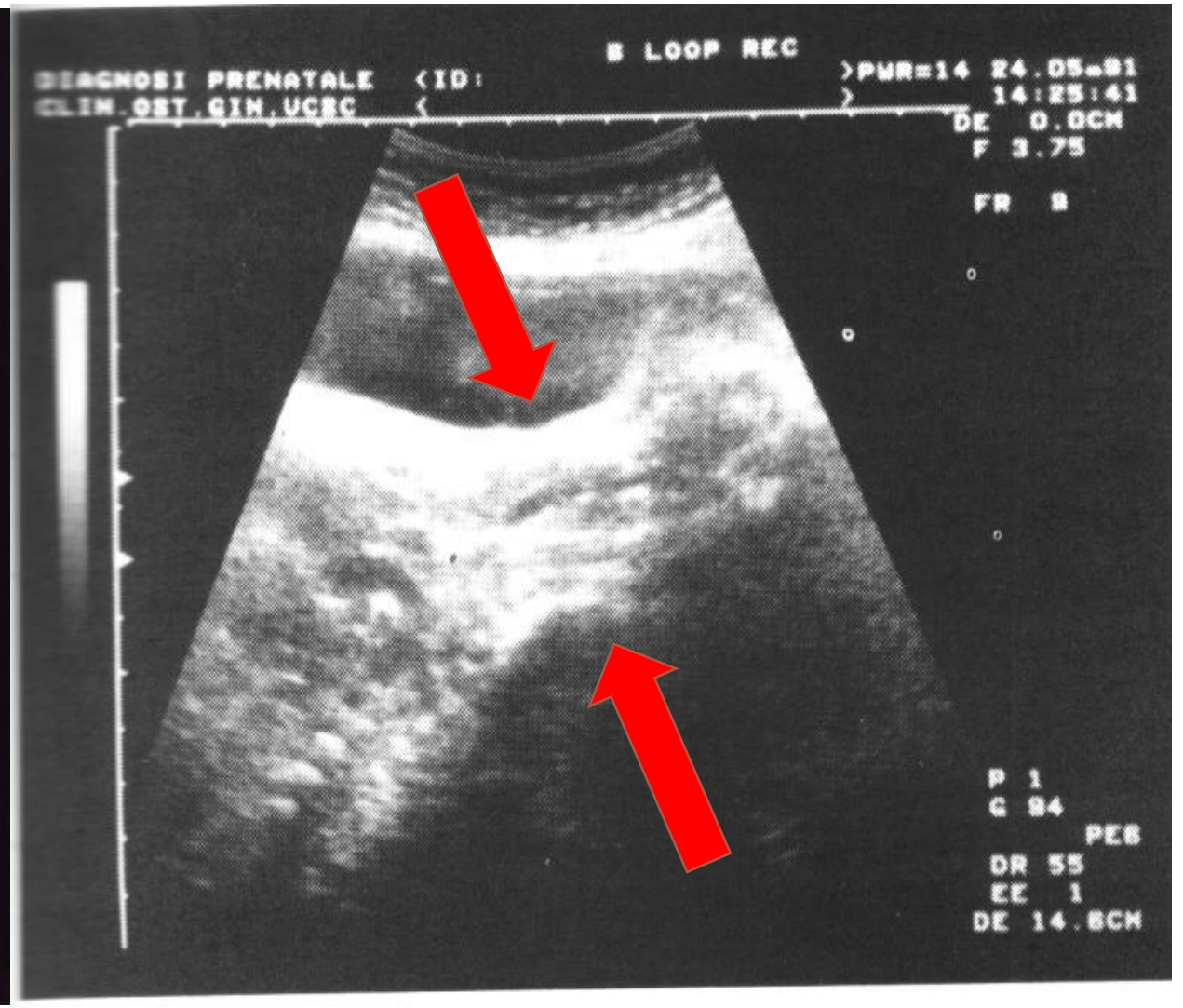
US PICTURE OF FETAL GOITER BEFORE AND AFTER THE INJECTION OF THYROXINE IN AMNIOTIC CAVITY : FETAL GOITER *DISAPPEARENCE 9 DAYS AFTER*

Left lobe of fetal thyroid



Right lobe of fetal thyroid

FETAL GOITER *DISAPPEARENCE 9 DAYS AFTER*



«EARLY PRENATAL DIAGNOSIS AND THERAPY OF FETAL HYPOTHYROID GOITER»

FETAL DIAGN THER. 1992; 7: 138-43

NOIA G, DE SANTIS M, TOCCI A, MAUSSIER ML, D'ERRICO G, BIANCHI A, ROMAGNOLI C, MASINI L, CARUSO A, MANCUSO S

« EFFICACY OF ORAL IODIDE THERAPY ON NEONATAL HYPERTHYROIDISM CAUSED BY MATERNAL GRAVES' DISEASE »

FETAL DIAGN THER. 2000; 15 (2): 122-6

MARIGLIANO G, ZUPPA AA, FLORIO MG, SCAPILLATI ME, GIRLANDO P, CRESCIMBINI B, CAFFORIO C, *NOIA G,* CAVALIERE AF, TORTOROLO G

INTRAMNIOTIC APPROACH

Ultrasound-guided amnioinfusion of the urine of the fetus with obstructive pathology ,collected first from the bladder and injected around the body of the fetus to facilitate swallowing

AUTO - AMNIOINFUSION

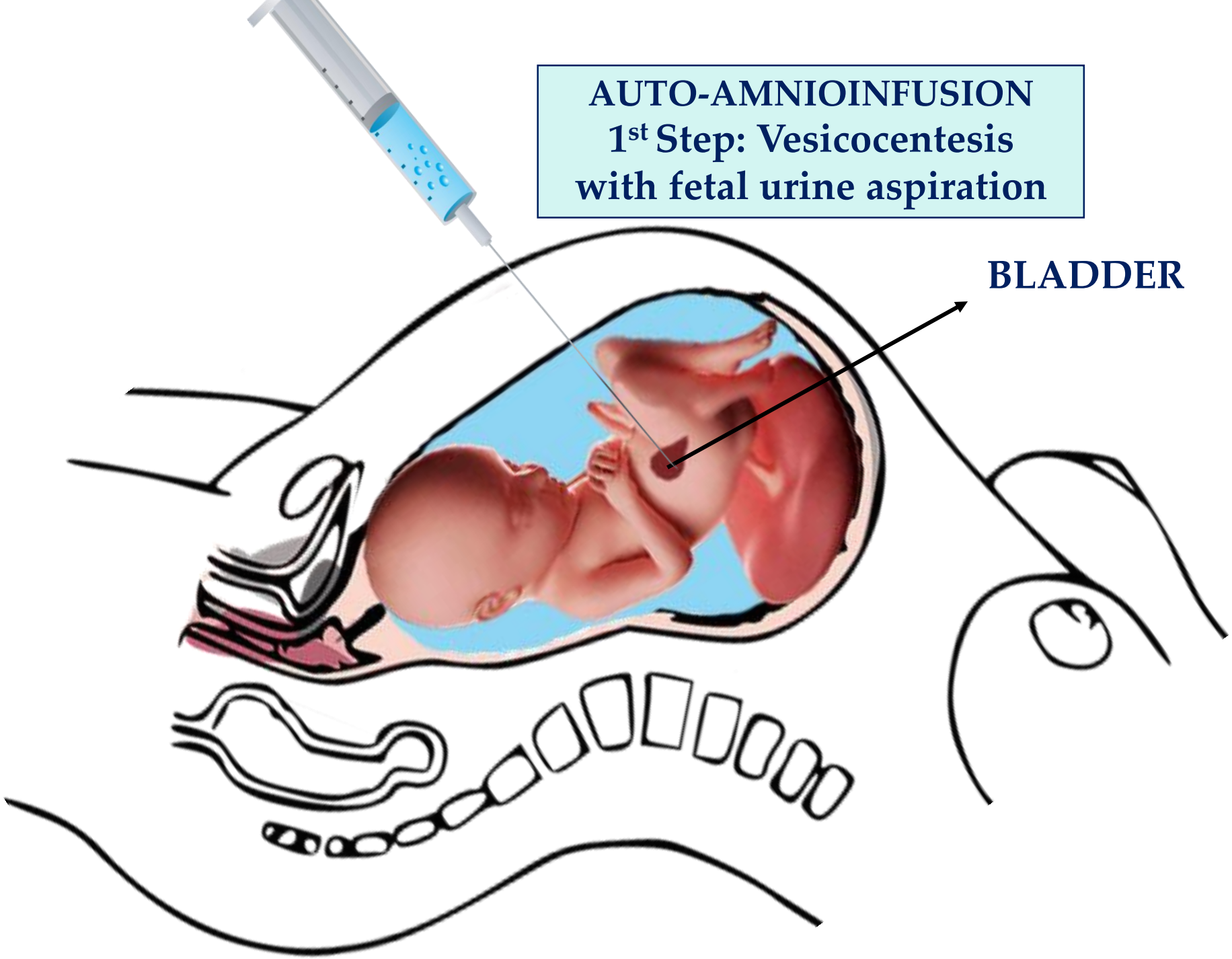
Patient with fetal obstructive uropathy (posterior urethral valves with fetal megacystis and Anidramnios).

Cystocentesis, Paracentesis, Thoracentesis, Auto-amnioinfusions, ultrasound guided after maternal and fetal analgesia, fetal urine aspiration and infusion of "own" fetal urine (instead of saline) in amnios from 24 weeks.

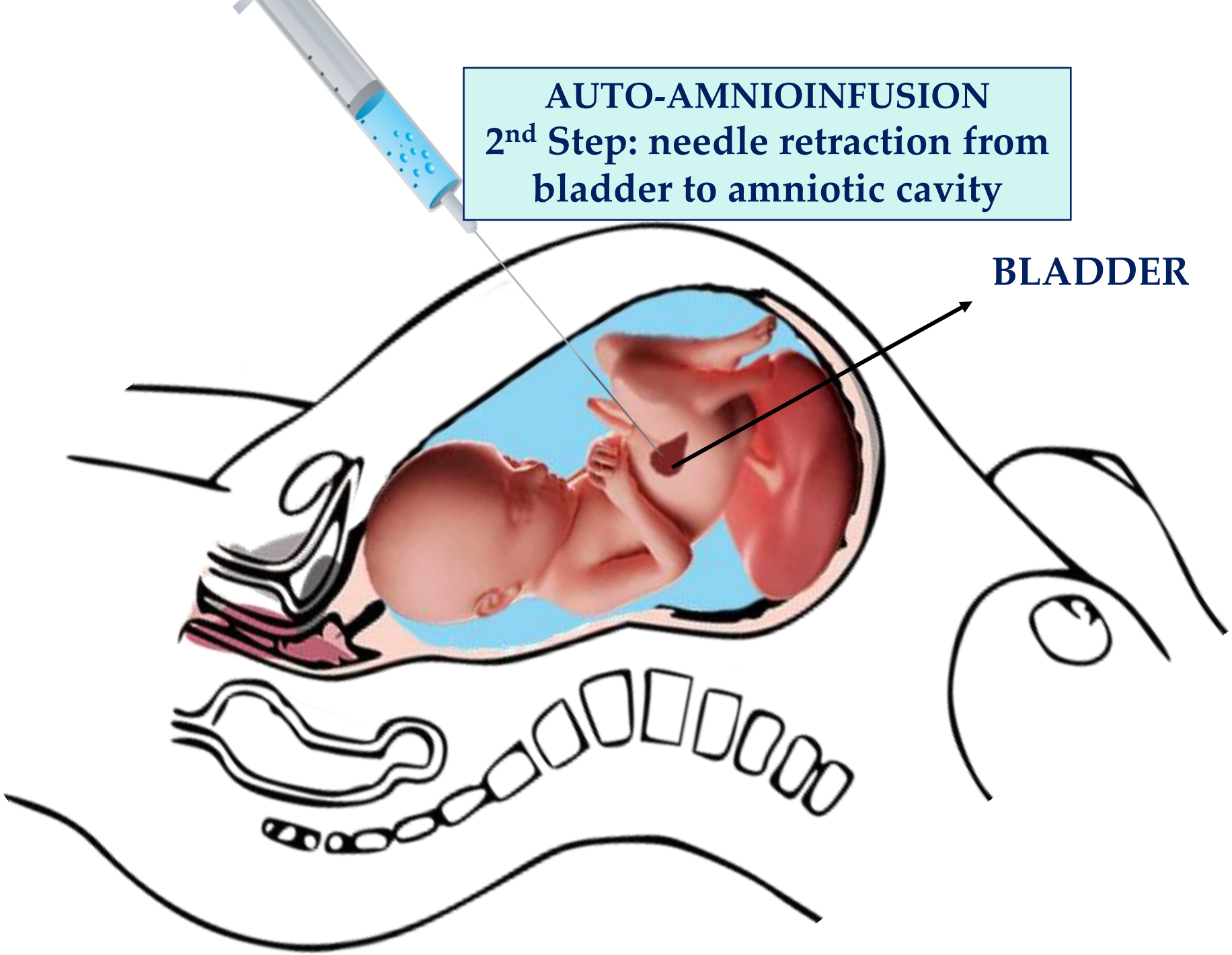
12 Procedures (7 Autoamnioinfusions, 3 paracentesis, 2 thoracentesis) until birth at 33 weeks, discharge in 22 days, electrocution of the urethra valves, for 2 times.

Normal follow-up to 5 years.

AUTO-AMNIOINFUSION
1st Step: Vesicocentesis with fetal urine aspiration

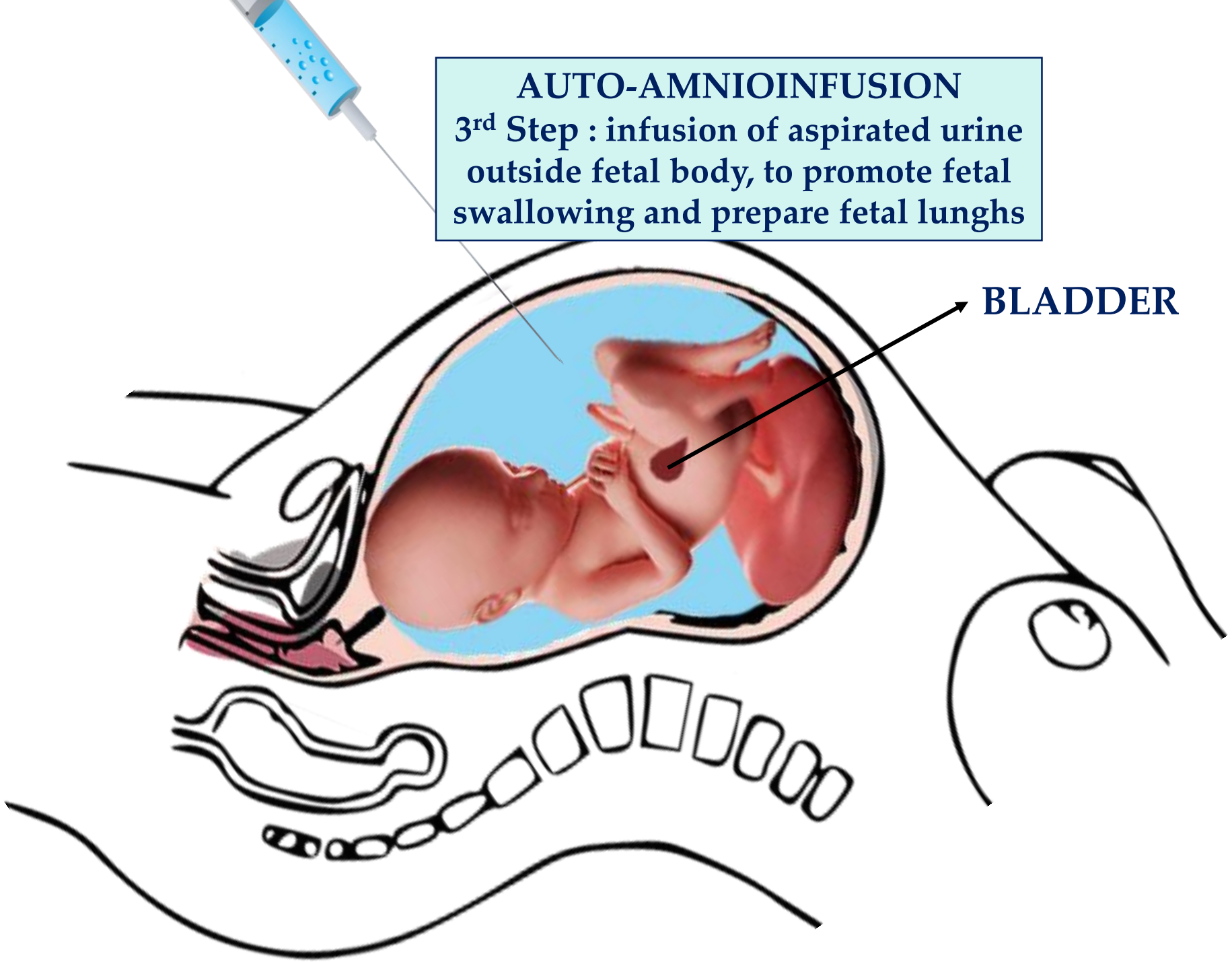


AUTO-AMNIOINFUSION
2nd Step: needle retraction from bladder to amniotic cavity



AUTO-AMNIOINFUSION

3rd Step : infusion of aspirated urine outside fetal body, to promote fetal swallowing and prepare fetal lunghs



INTRAMNIOTIC APPROACH

Ecoguided prenatal invasive amnioreduction complementary to emergency cerclage

16 CASES OF ACUTE CERVICAL INCONTINENCE, WITH AMNIOTIC SAC ERNIATION IN VAGINA : *EMERGENCY CERCLAGE AND CONTEMPORARY AMNIOREDUCTION TO DIMINISH INTRAMNIOTIC PRESSURE AND TO PROMOTE THE SEARCH FOR THE FLAPS OF UTERINE CERVIX*

EMERGENCY CERCLAGE AND CONTEMPORARY AMNIOREDUCTION

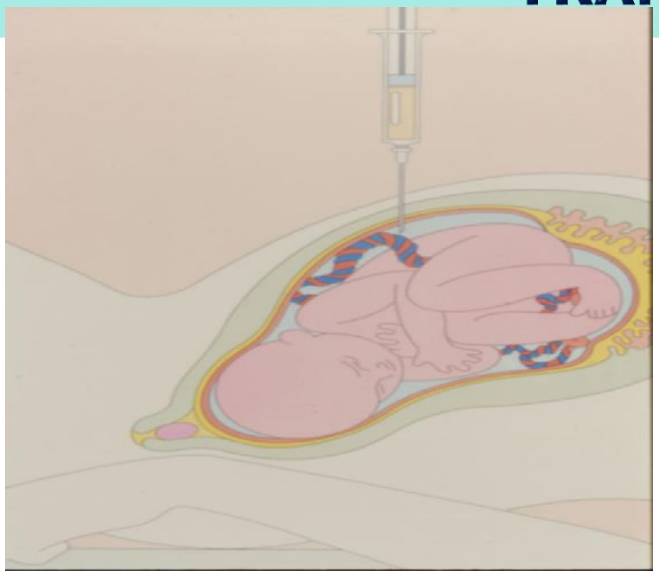
16 FULL TERM BABIES

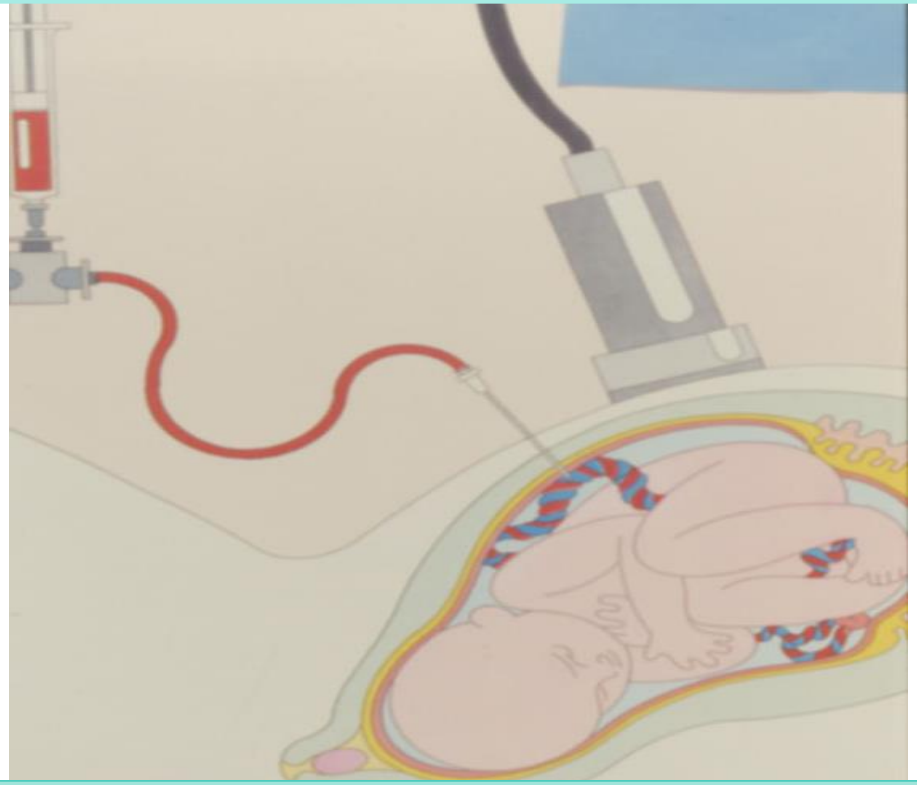
WITH GOOD FOLLOW UP AT 8 YEARS

INTRAVASCULAR APPROACH

Ecoguided prenatal invasive Intravascular and \ or Intraperitoneal fetal transfusion For severe fetal anemia or fetal trombocytopenia

THE NATURAL HISTORY OF Rh ISOIMMUNIZATION
INTRAVASCULAR APPROACH
CORDOCENTESIS AND ECOGUIDED INTRAVASCULAR TRANSFUSION (728 cases)





Survival (20 years) from 40% to 88%

Noia et al.
CLIN. EXP. OBST. & GYN.
ISSN: 0390-6663 - XXIX, 4, 2002

The highest coombs in the world: 1/65536
with good outcome (6 years) after *9 IUFT*

2 RECENT CASES OF SEVERE FETAL ANEMIA

- Fetal Hb at first sampling =

  2,9 G/DL(1°CASE) 2,6 (2° CASE)

- **Platelets at first sampling: 54.000**
- **Platelets at second sampling: 51.000**

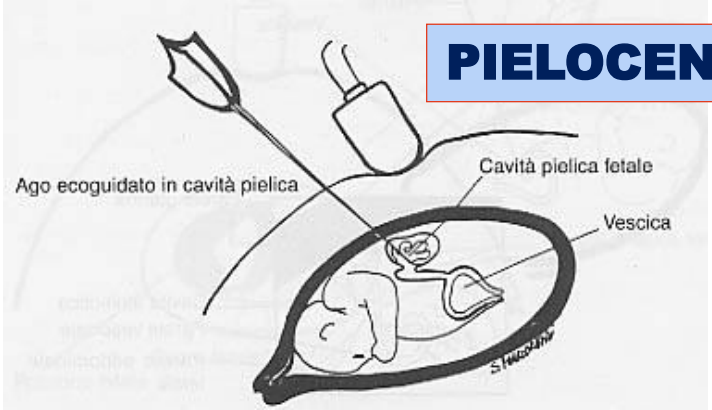
- **Intravascular intrauterine transfusion ultra sound guided** with packed red cells with Hct>86%.

THE FIRST BABY WAS BORN AT 40 WEEKS: **CT, *Hb=13.2 g/dl.***

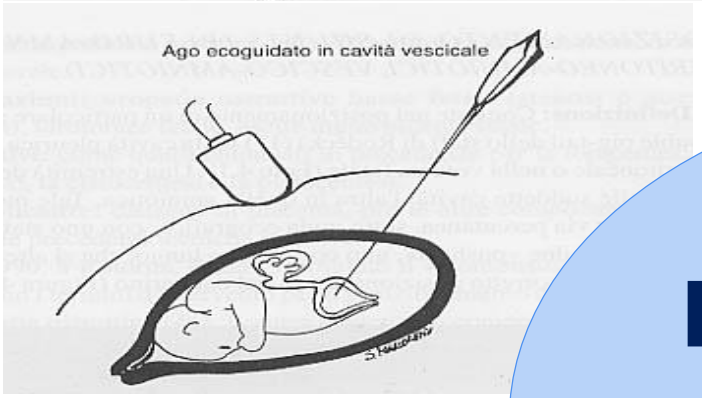
THE SECOND BABY WAS BORN AT 31 WEEKS: **CT, *Hb=9.9 g/dl***

BOTH CHILDREN AT LONG FOLLOW UP (6 YEARS): GOOD OUTCOME

FETAL THERAPY



PIELOCENTESIS



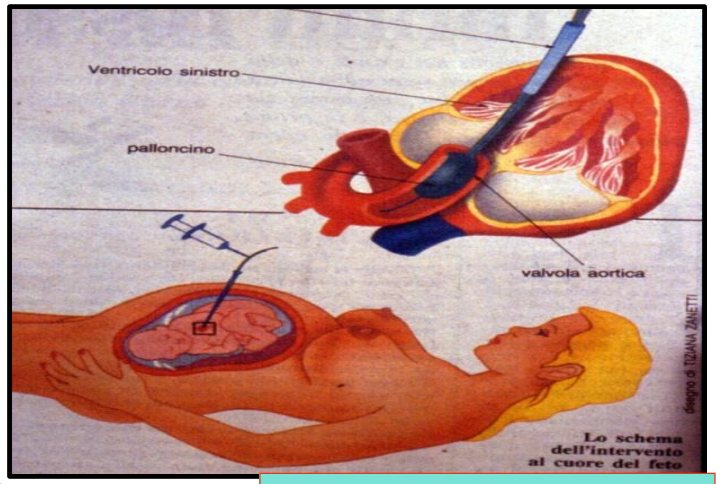
CISTOCENTESIS

THORACENTESIS

PARACENTESIS

INTRA/CELOMATIC CAVITY

INVASIVE ECO GUIDED: approaches that CROSS the fetal body



INTRACARDIAC *PRENATAL VALVULOPLASTY*

ECO GUIDED FETAL OVARIC ASPIRATION

PRENATAL THERAPEUTICAL AND PALLIATIVE TREATMENS

INTRAURINARY APPROACHES

(Cistocentesis, Pielocentesis and Shunt)

INTRASEROUS CAVITIES APPROACHES

(Thoracentesis and Paracentesis)

EVIDENCE OF THE FETAL PAIN

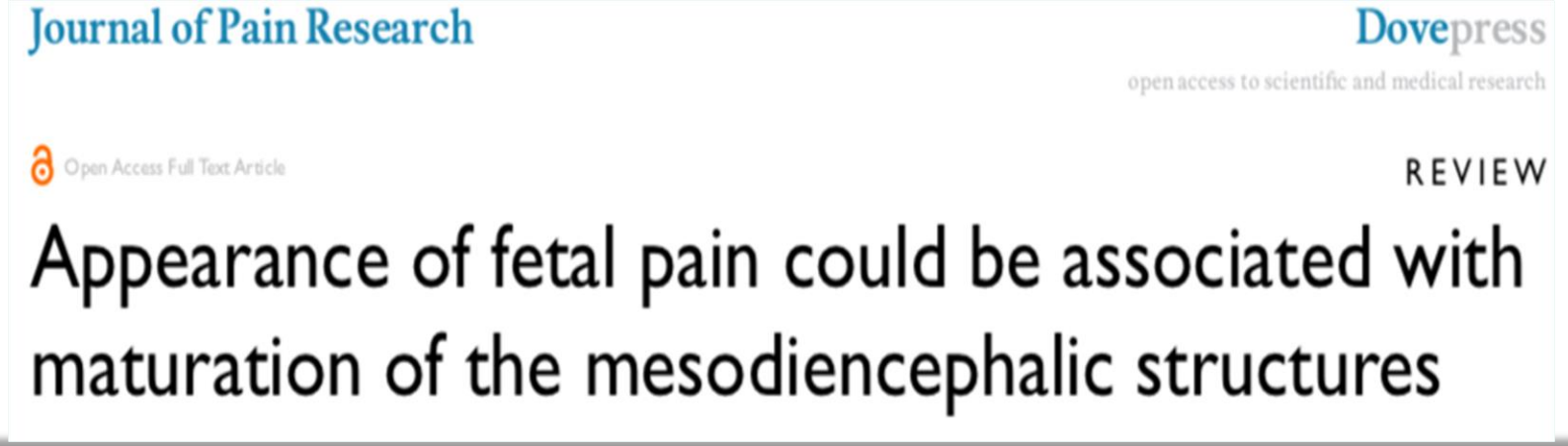
- A meta-analysis of 217 studies, including 157 highly specific on fetal pain, shows that the **fetus has been able to perceive pain since the second trimester.**

Bellieni C.V, Buonocore G..October 2011, Department of Pediatrics, Obstetrics and Reproduction Medicine, University of Siena– Italy

- This data is supported by the evidence of the development of **the spino-thalamic pathways (around 20° GA)** and by the connections of the thalamus with the primitive cortex (after the 23rd GA).

Glover V. «The fetus may feel pain from 20 weeks»; in The Fetal Pain Controversy, Conscience. 25:3, 2004, 35-37)
Anaesthesiology. 18:2, 2004

FETAL PAIN



- **THE FETUS PERCEIVES A FIRST FORM OF PAIN ALREADY FROM THE 15TH WEEK OF GESTATION.**
- ***The reticular formation of the Mesodiencephalon plays a key role in the transmission and dissemination of pain and is attributable to the total perception of the fetus*.**

Sekulic, Slobodan, et al. ***"Appearance of fetal pain could be associated with maturation of the mesodiencephalic structures." Journal of pain research 9 (2016): 1031.***

FETAL ANALGESIA AND FETAL PALLIATION

A set of methods providing for invasive and non-invasive eco-guided interventions aimed at:

A) temporary care for the fetus in order to obtain a clinical goal ("life saving" type) (called **CLINICAL PALLIATION)** or

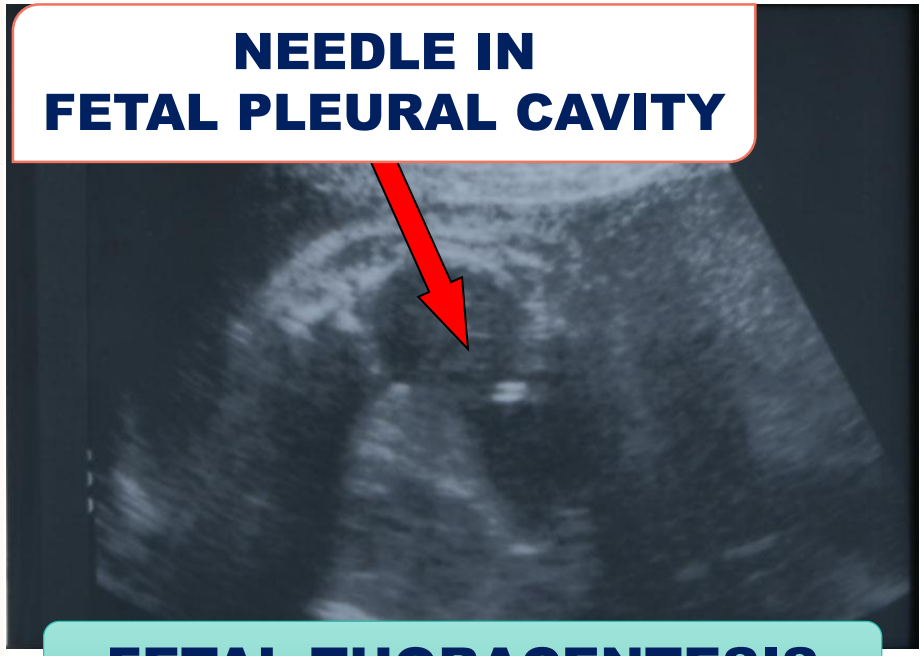
B) to alleviate the sensitivity to the pain of the fetus due to distension of the serous stuctures rich in nervous painful terminations (called **NOCICECTIVE PALLIATION)**

108 PROCEDURES
FETAL ANALGESIA (86)
CURARIZATION (22)

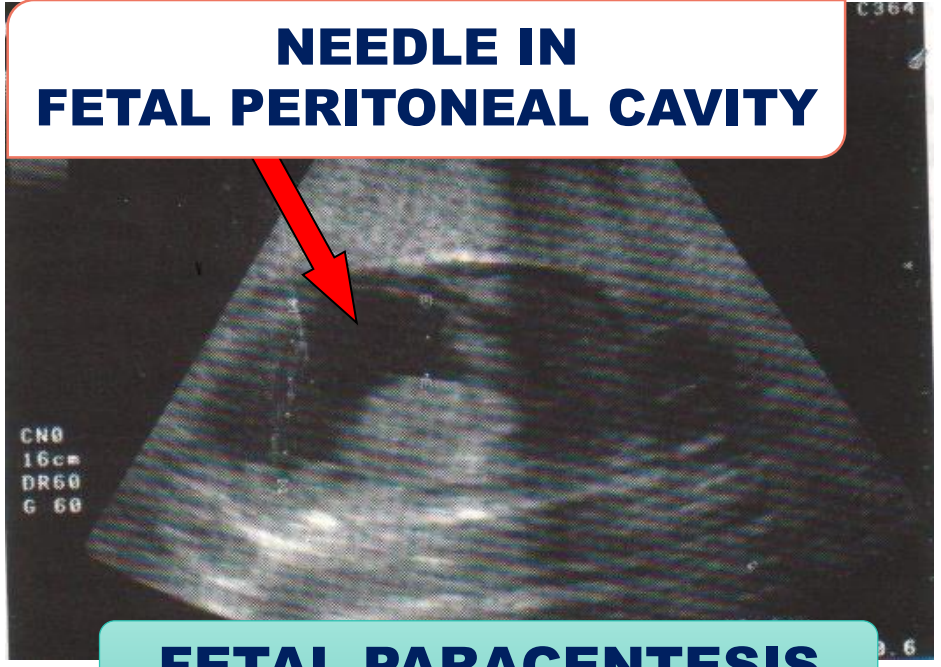
Fetal Analgesia

	AMOUNT	LATENCY PERIOD	EFFECTS INTERVAL	WAY
FENTANIL	0,2 mg/Kg	1 minute	1 hour	intravascular
LIDOCAINE	0,2 mg/Kg	1 minute	1 hour	percutaneous

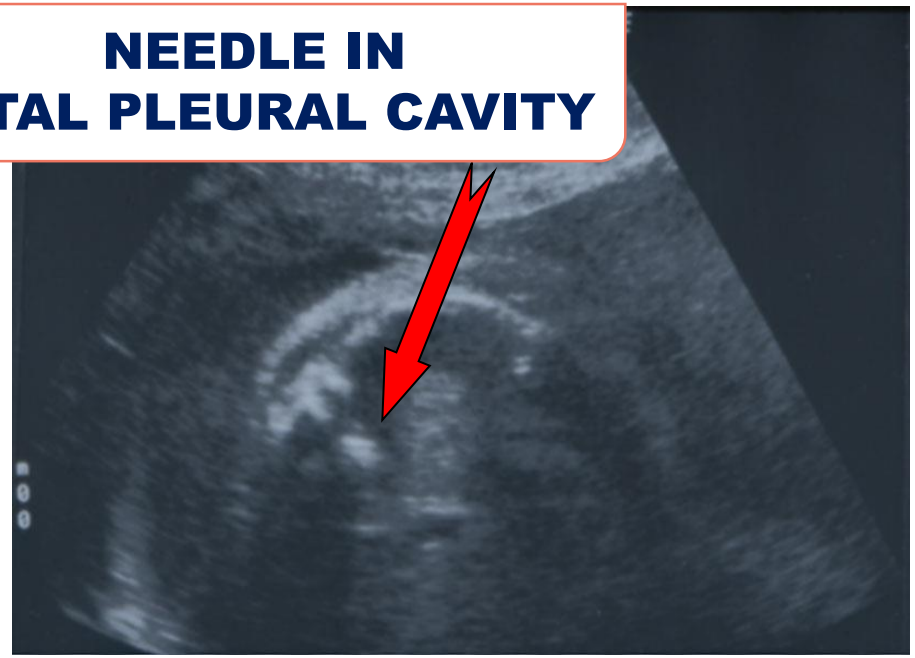
→ 86 procedures



FETAL THORACENTESIS



FETAL PARACENTESIS



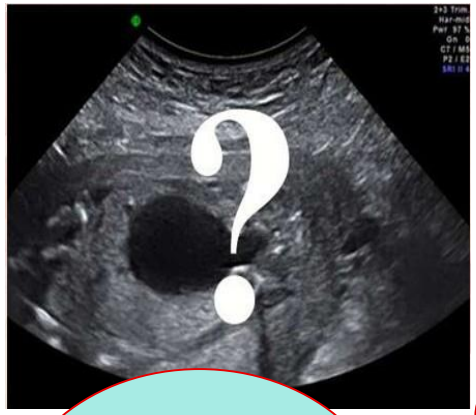
NOIA G. ET AL.

MULTIMODAL APPROACH IN INVASIVE FETAL THERAPY

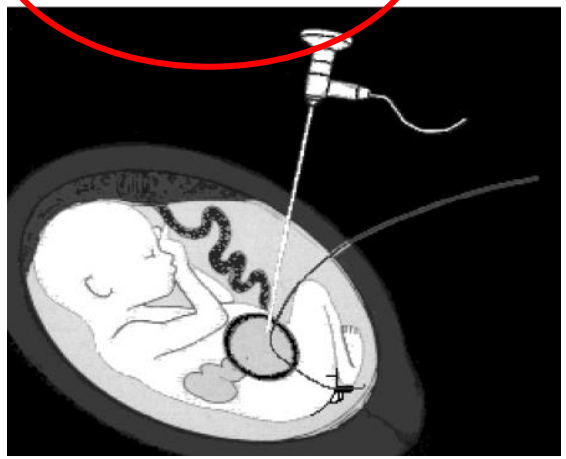
ACTA OBSTET GYNECOL SCAND. 1999;78(2): 160-4

FETAL MEGABLADDER

INTRAURINARY THERAPEUTIC APPROACH

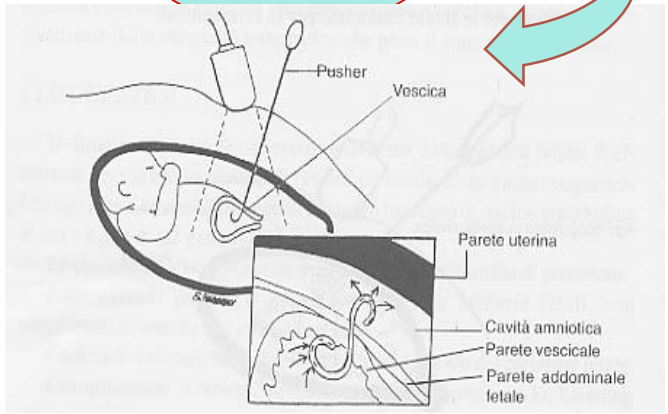


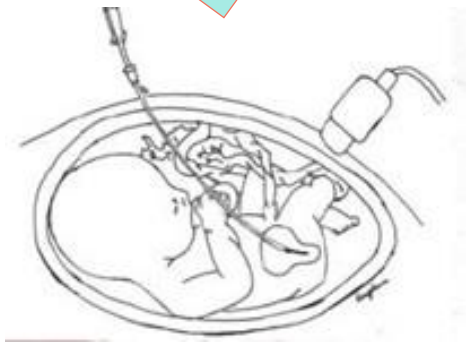
Fetoscopic approach

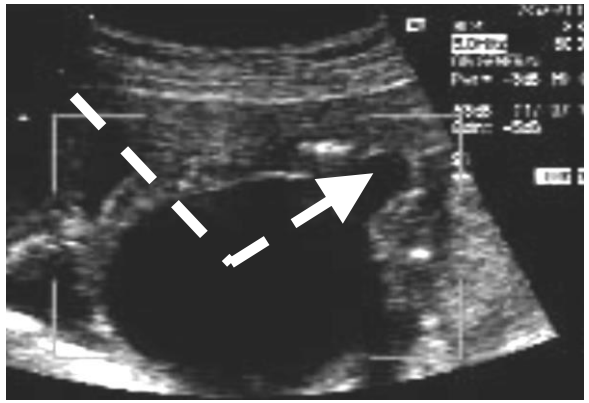


Serial cistocentesis

Vesico amniotic SHUNT

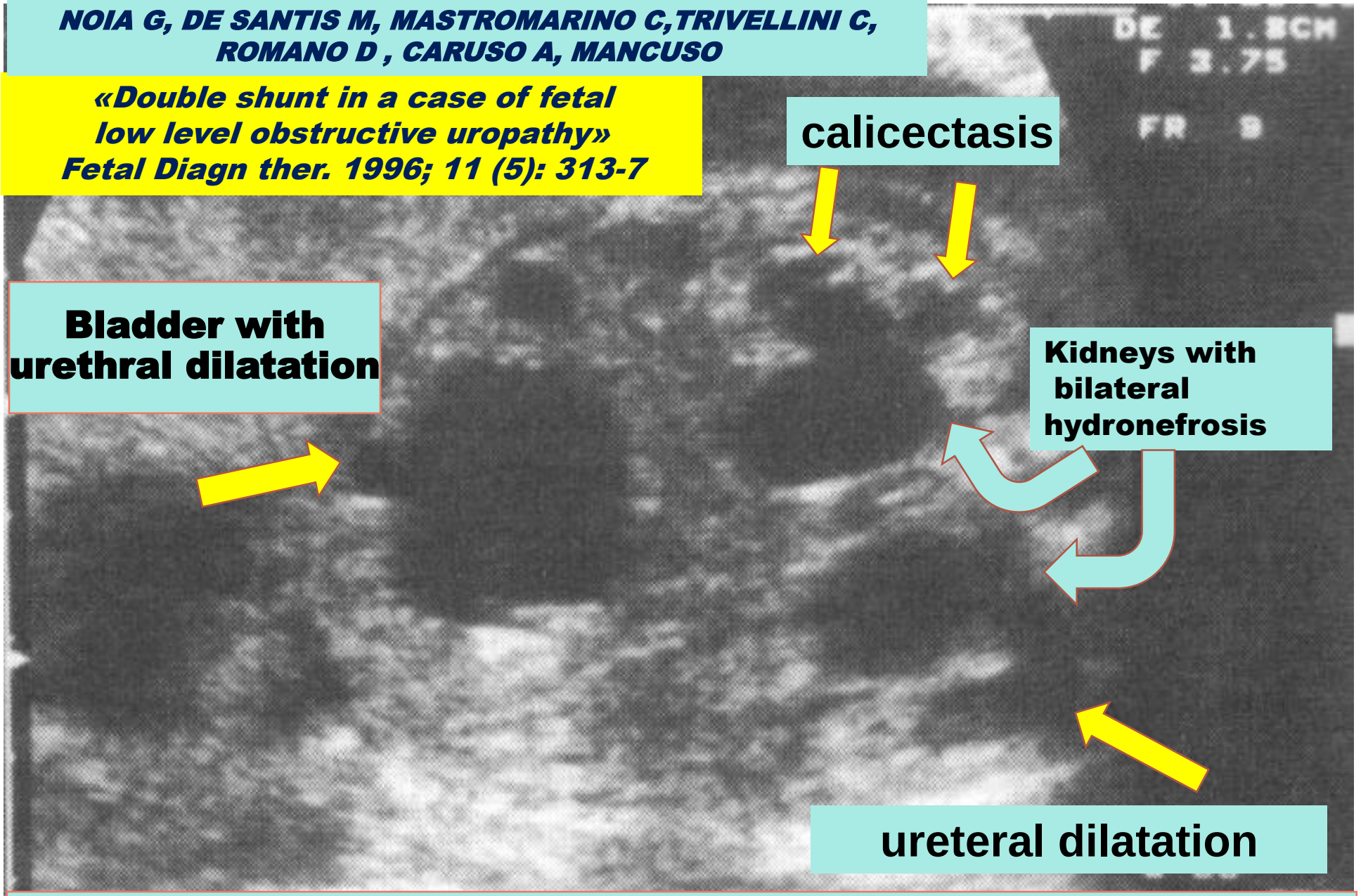






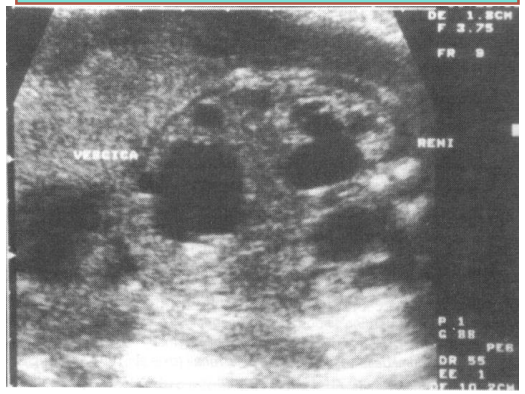
NOIA G, DE SANTIS M, MASTROMARINO C,TRIVELLINI C, ROMANO D , CARUSO A, MANCUSO

«Double shunt in a case of fetal low level obstructive uropathy»
Fetal Diagn ther. 1996; 11 (5): 313-7

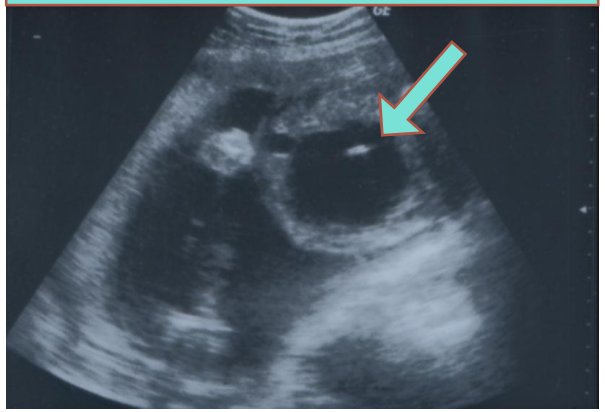


Low fetal ostructive uropathy with megabladder and bilateral hydronefrosis

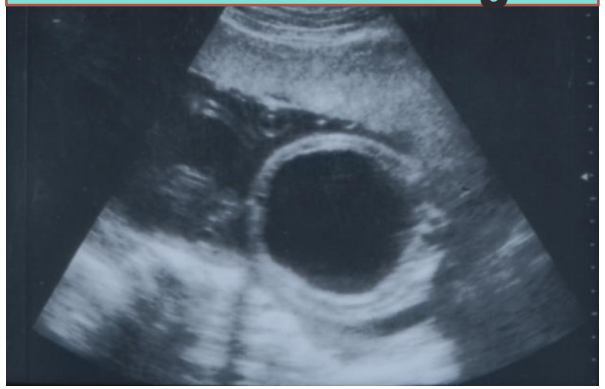
Before shunting

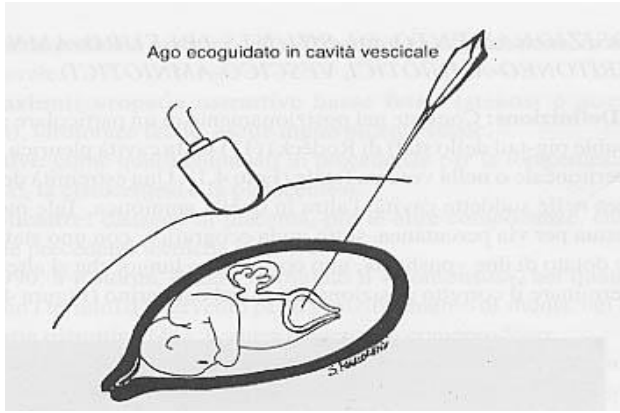


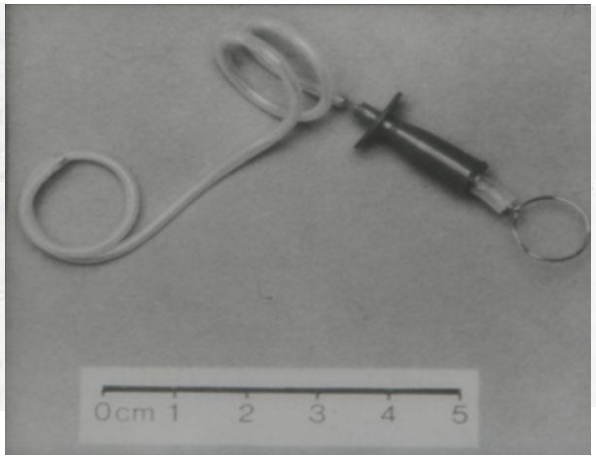
After the 1 shunting

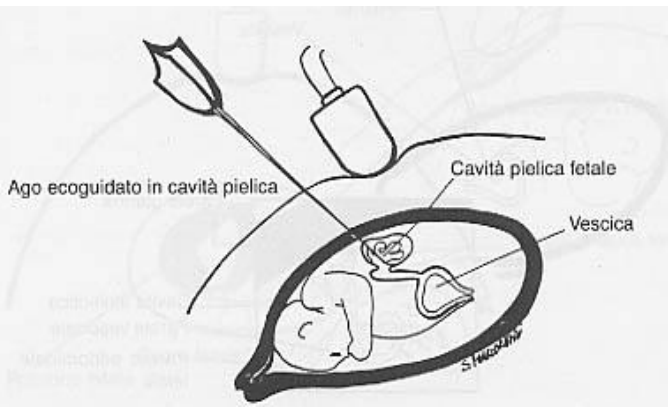


Amniotic fluid normal restoring after 2 shunting









NOIA G, DE SANTIS M, MASTROMARINO C,TRIVELLINI C, ROMANO D , CARUSO A, MANCUSO

«Double shunt in a case of fetal low level obstructive uropathy»

Fetal Diagn ther. 1996; 11 (5): 313-7

Newborn with prenatal double shunt (vesical-amniotic and peritoneal-amniotic shunt)

NOIA et al. «Double shunt in a case of fetal low level obstructive uropathy» Fetal Diagn Ther. 1996; 11 (5): 313-7

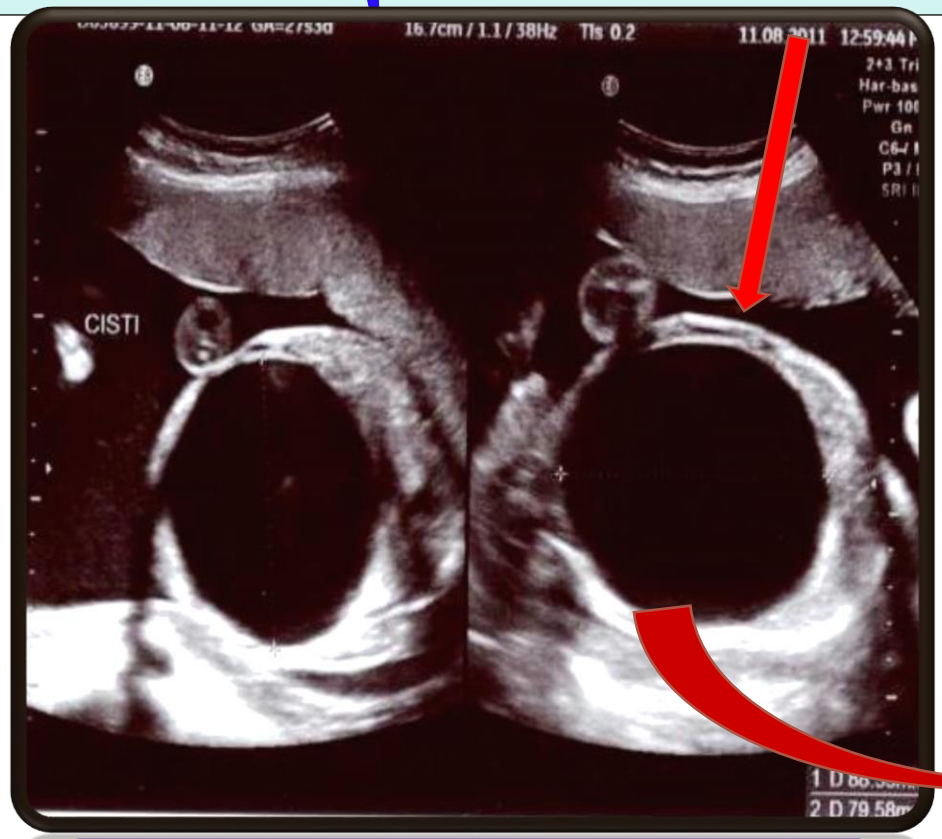
Post natal shunt location

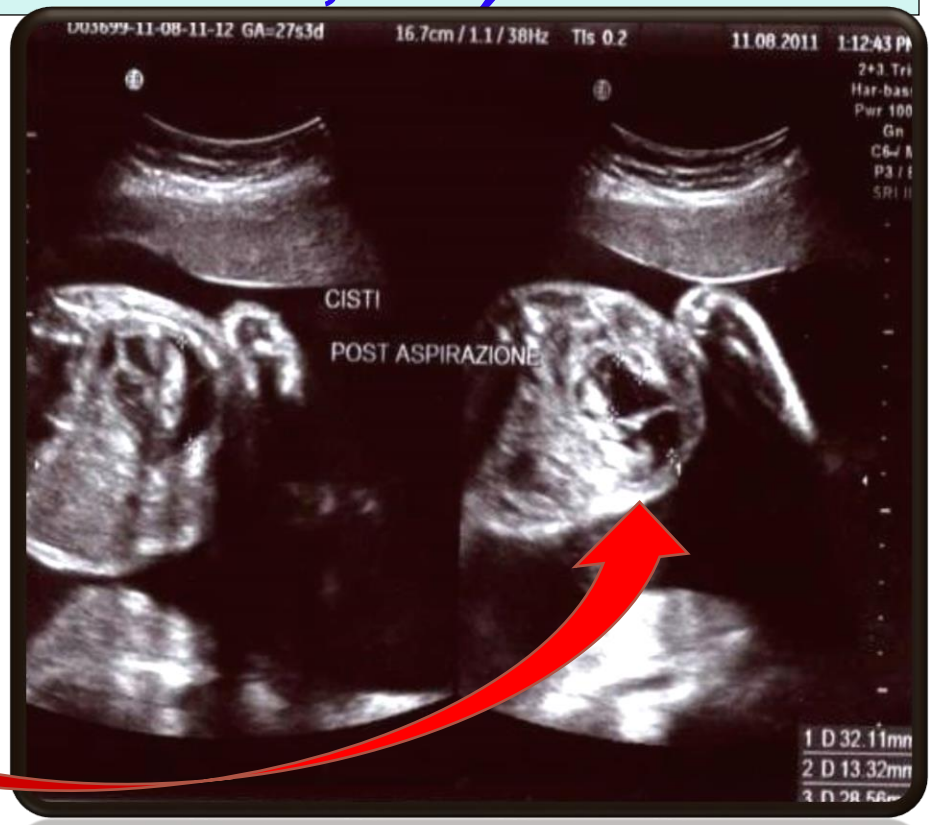
The prenatal palliatives treatments (drainages of large abdominal cysts to avoid fetal decompensation) as life saving procedures until the most appropriate period for premature birth

8 Drenaiges of large fetal renal cyst (non ovarian) with histological diagnosis of *segmental renal dysplasia*

NOIA et al.,-A rare case of renal displasia : prenatal and postnatal management

(FETAL AND PEDIATRIC PATHOLOGY ,2013)





8,8 x 7,9 x 74 mm

32x13x29 mm

FETAL AND MATERNAL PALLIATIVE TREATMENTS AS ALTERNATIVE ANSWER TO SELECTIVE FETICIDE :

21 SURVIVING CHILDREN (GOOD FOLLOW-UP TO 4 YEARS)

A) 83.3% of survival (10 SURVIVING CHILDREN)

after **37 invasive interventions of nocicective and clinical palliation (vesical,thoracic and peritoneal drainages) in 6 twin discordant pregnancies (1 normal and 1 malformed) recommented for the selective feticide of the malformed twin !**

B) 100% of survival in 2 quadruplet and 1 triplets pregnancies !

(11 SURVIVING CHILDREN)

(recommented for the selective feticide of two twins in each)

SUBMITTED TO EMERGENCY CERCLAGE

Preventive and emergency cervical cerclage

- 11/11 alive and well (29/32ww)newborns
- (100% of survival) in 2 quadruplet and 1 triplets, spontaneous pregnancies, counseled for selective feticide at 17, 13 and 12 weeks of gestation.

«Prenatal detection of megacystis: not always an adverse prognostic factor. Experience in twenty-two consecutive cases in a tertiary referral center, with complete neonatal outcome and long-term follow-up»

Pellegrino M., Visconti D., Doria L., Manzoni C., Grella M.G., Catania V.D., Masini L., Caruso A., Noia G.

Journal of Pediatric Urology 2017

Conclusion 1

32 YEARS OF ACCOMPANIMENT
TO THE PRENATAL FRAILNESS
1990 - 2022

1000 cases elegible
by fetuses life – limiting followed
from 1990 to September 2005

94% of acceptance rate
to continue pregnancy

CLINICAL SEQUELA OF TREATED CONGENITAL ANOMALIES

with life limiting condition

from 2005 to 2016 - 328 CASES *with* ***89%*** *of acceptance rate to continue pregnancy*

• GENETIC	70 (21,34%)	
• SNC	66 (20,12%)	
• RENAL	44 (13,41%)	**83,45 %**
• GASTROENTERIC	43 (13,11%)	
• LYMPHOANGIOMATOSIS	35 (10,67%)	
• CARDIAC	16 (4,87%)	
• BONES AND LIMBS	12 (3,66%)	
• TWIN	7 (2,13%)	
• SINDROMIC	4 (1,21%)	
• MISCELLANEA	31 (9,45%)	

From 2016 to 2021 - 586 CASES *with 87% of acceptance rate to continue pregnancy*

HOSPICE PERINATALE POLICLINICO GEMELLI E FONDAZIONE IL CUORE IN UNA GOCCIA ONLUS
LUGLIO 2016 - DICEMBRE 2021

PERIODO	GRAVIDANZE SEGUITE	CONSULENZE	TOTALE CASI
LUGLIO 2021 - DICEMBRE 2021	19	35	54
GENNAIO 2021 - GIUGNO 2021	21	32	53
LUGLIO 2020 - DICEMBRE 2020	32	34	66
GENNAIO 2020 - GIUGNO 2020	23	47	70
LUGLIO 2019 - DICEMBRE 2019	16	35	51
GENNAIO 2019 - GIUGNO 2019	22	46	68
AGOSTO 2018 - DICEMBRE 2018	23	26	49
FEBBRAIO 2018 - LUGLIO 2018	28	40	68
AGOSTO 2017 - GENNAIO 2018	33	25	58
FEBBRAIO 2017 - LUGLIO 2017	15	10	25
LUGLIO 2016 - GENNAIO 2017	23	1	24
TOTALE	**255**	**331**	**586**

SHARED PATH

BIRTH AND NEONATAL ASSISTENCE

CEC o DC

DELIVERY ROOM

COMFORT CARE

DELIVERY ROOM

PERINATAL HOSPICE

HAND-LIFE CARE

DELIVERY ROOM

NICU SUB-NICU

HAND-LIFE CARE

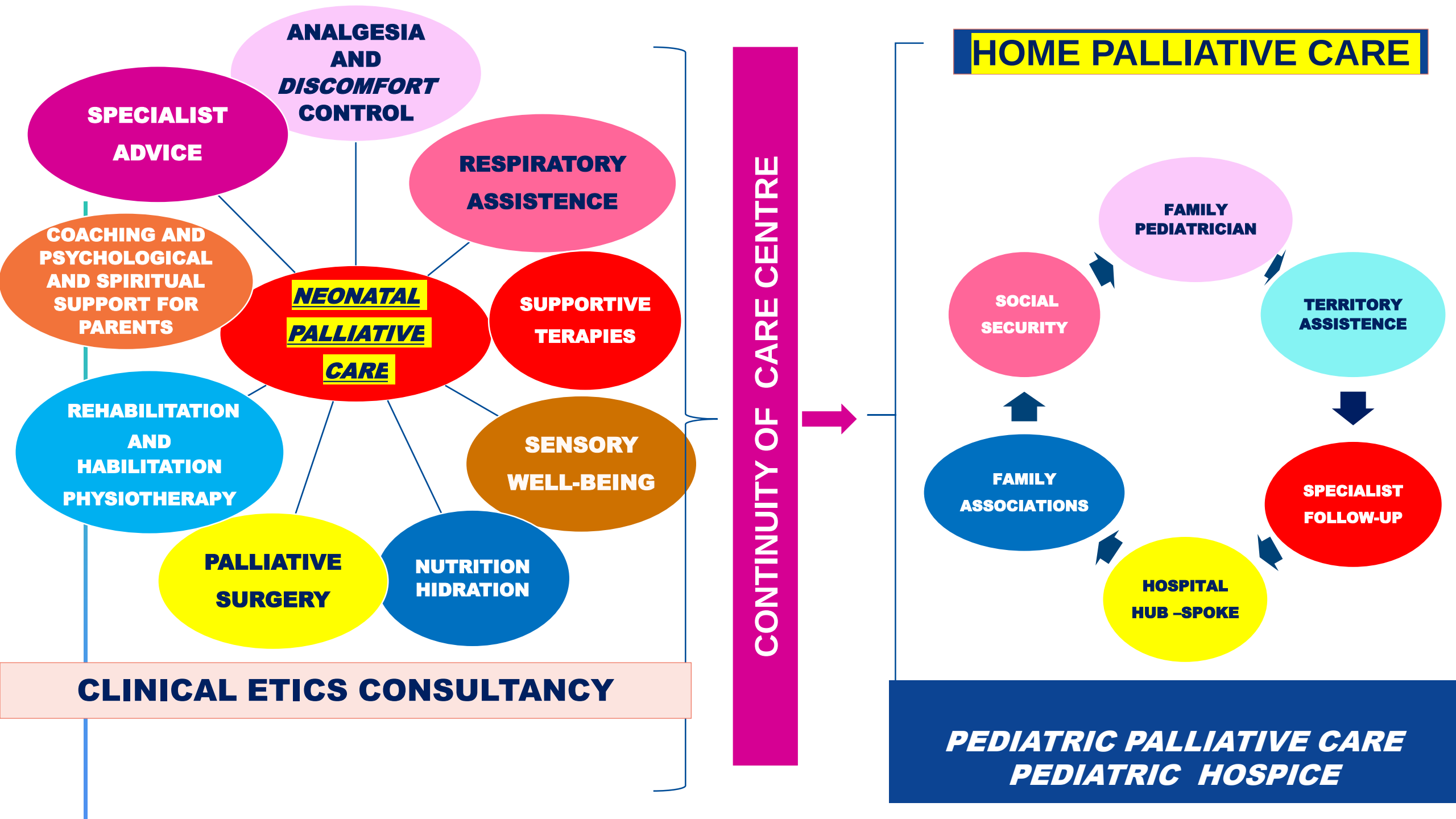
PALLIATIVE CARE

HOME PALLIATIVE CARE / PEDIATRIC HOSPICE

CEC o DC

NEONATAL PALLIATIVE CARE → PEDIATRIC CARE

CEC = CLINICAL ETHICS CONSULTANCY ---- DC = SHARED DOCUMENTS


ANALGESIA AND DISCOMFORT CONTROL
SPECIALIST ADVICE
RESPIRATORY ASSISTENCE
COACHING AND PSYCHOLOGICAL AND SPIRITUAL SUPPORT FOR PARENTS
NEONATAL PALLIATIVE CARE
SUPPORTIVE TERAPIES
REHABILITATION AND HABILITATION PHYSIOTHERAPY
SENSORY WELL-BEING
PALLIATIVE SURGERY
NUTRITION HIDRATION
CLINICAL ETICS CONSULTANCY
CONTINUITY OF CARE CENTRE
HOME PALLIATIVE CARE
FAMILY PEDIATRICIAN
TERRITORY ASSISTENCE
SPECIALIST FOLLOW-UP
HOSPITAL HUB –SPOKE
FAMILY ASSOCIATIONS
SOCIAL SECURITY
PEDIATRIC PALLIATIVE CARE
PEDIATRIC HOSPICE

PERINATAL HOSPICE PATWAY

DELIVERY ROOM : in 2 cases out of 29 ***(6,89 %)*** ,the death occurred during labor and in 20 case out of 29 ***(68,96 %)***,the death occurred in delivery room .***Comfort care was put in place.***

PERINATAL HOSPICE : in 7 cases out of 29 (***24,1 %***) death occurred in the Perinatal Hospice and ***End-life care was implemented***

29 cases

- 9 - Trisomy 18
- 4- Acrania - Anancephaly
- 3- Giant Cistic Hygroma
- 3- Potter Syndrome
- 2- Trisomy 13
- 2- Thanatoforic Dysplasia
- 1- Alkuraya Kucinscas Syndrome
- 1- Trisomy 22
- 1- Microcephaly
- 1 -Polimalformative Syndrome – Cardiopathy
- 1 -AlobarHoloprosenkephaly
- 1- Encefalocele

PERINATAL HOSPICE PATWAY - NEONATAL PALLIATIVE CARE

28 cases were followed up in Neonatal Intensive Care Unit (Nicu):

A) End-life care was implemented in 13 cases (46,42 %)

B) 1 hospitalization in progress (3,57 %) and 14 cases (50 %) were discharged to home palliative care

28 cases

12 - Trisomy 18 (2 live)
4 - Lobar Holoprosenkephaly
2 - Encephalocele
2 - Polycystic Renal Displasia (1 Renal Transplantation)
1 - Coffin Siris Syndrome
1 - Joubert Syndrome
1 - Microcephaly
1 - Face-neck-collo-toracic lynphoangiomatosis
1 - Polimalformative Syndrome (Orofaciodigital Syndrome)
1 - Polimalformative Syndrome and cromosomal duplication 8
1 - Bone Dysplasia
1 - Arthrogryposis

CONCLUSION 2

TOWARD A MODEL OF GLOBAL ASSISTENCE

HEALING NEEDS OF MOTHER AND FETUS

Mono-relational Model

PSYCOLOGICAL AND SOCIAL NEEDS OF THE WHOLE FAMILY

Multi-relational Model

COORDINATED INTERVENTIONS BY ALL THE HEALTH WORKERS INVOLVED

Inter-relational Model

FROM POSTNATAL CARE TO ANTENATAL CARE

PERINATAL HOSPICE

«SHARED MEDICINE»

CONCLUSION 3

THE STRENGTHS OF THE WELFARE MODEL PERINATAL HOSPICE OF THE GEMELLI POLICLINIC IN ROME

Taken in *antenatal care*

Model of Care that *works in 3 steps*: 1) clinical-scientific way of health care providers , 2) supportive-family and 3) spiritual approach (Fondazione il Cuore in una Goccia Onlus)

Presence of a *multidisciplinary and interdisciplinary team* that deals with problems on an ongoing basis with an empathic, globally relational and professionatly effective assistance.

***Consistency of care*, compliance with the accompanying route and coordination between health professionals.**

Creation of «Shared documents»

CONCLUSION 4

The culture of Perinatal Hospice is a response to total physical and psycological pain of the fetus, the couple and the whole family.This multidisciplinary and interdisciplinary approach is as if it were an embrace why :

1. ***Combines competence and hospitality***
2. ***Combines clinical evidence and relational empathy***
3. ***Combines service and compassion and***

ultimately it unites science and conscience
by bringing science closer to suffering !

The sole objective is an authentic service to the human person.

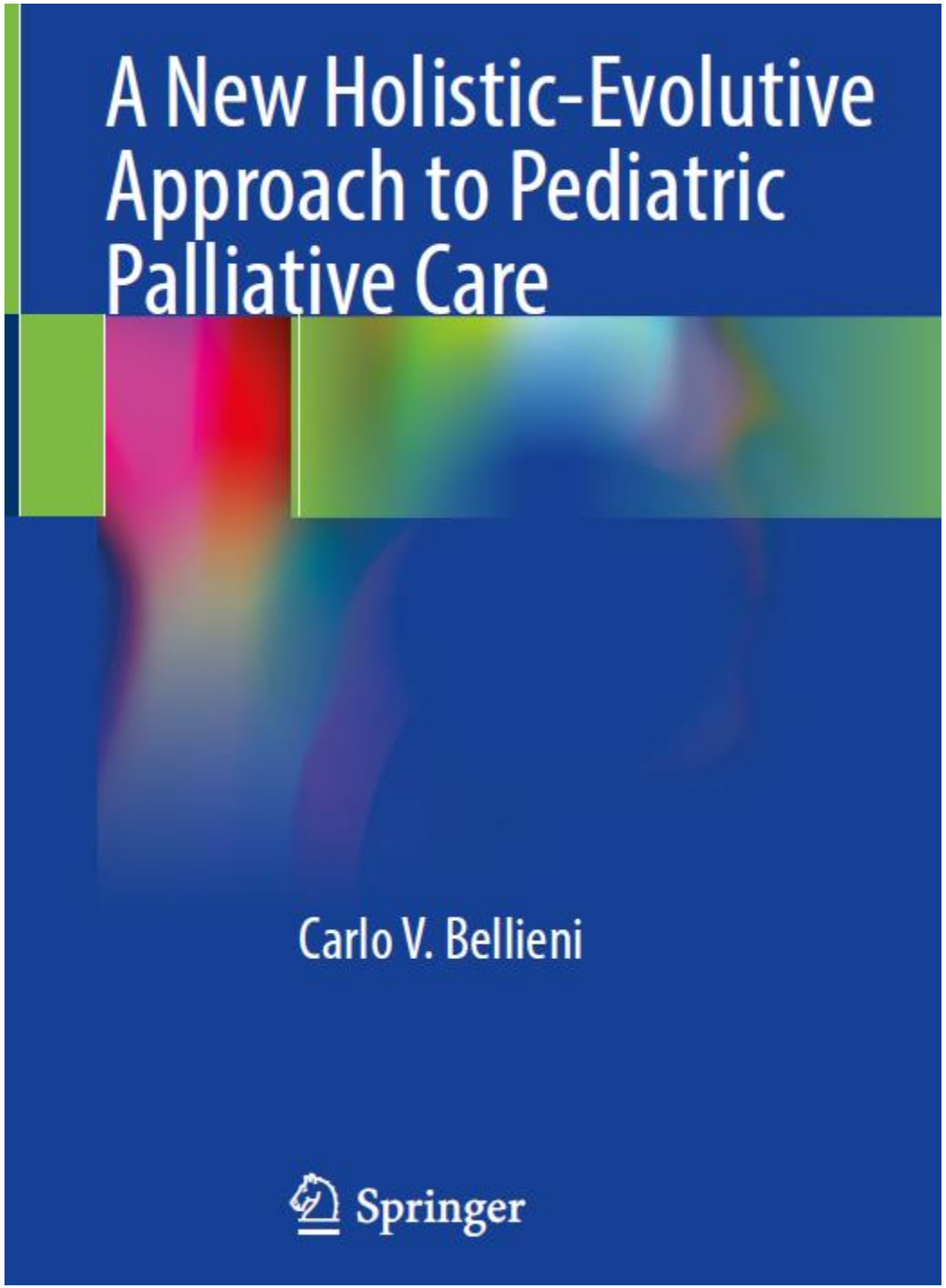
The Perinatal Hospice model of Policlinico Gemelli.Italian and international cultural and educational events

The commitment of the "Il Cuore in una Goccia" Foundation and the Hospice Team of the Policlinico Gemelli Hospital in spreading the culture of hospice has resulted in more than 100 cultural and educational events and initiatives over the last 4 years. Among the main ones:

«È dovere pastorale degli operatori sanitari di ispirazione cristiana adoperarsi per favorirne la massima diffusione nel mondo.» ***Samaritanus Bonus***

Fondazione
Il Cuore in una Goccia
Onlus

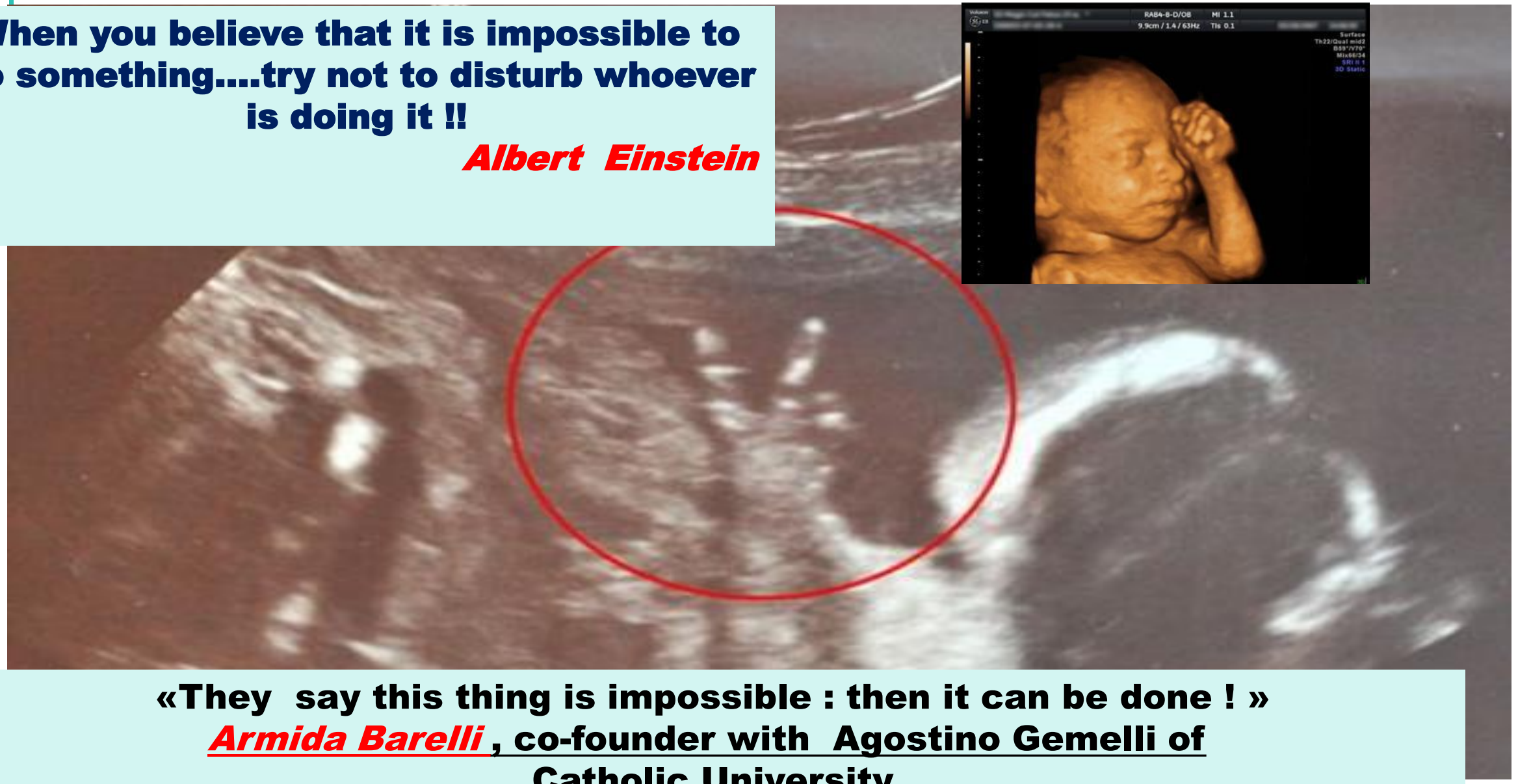
- ***YES TO LIFE! TAKING CARE OF THE PRECIOUS GIFT OF LIFE IN FRAGILITY - International Conference - Organized by Dicastero Laici, Famiglia e Vita and Fondazione il Cuore in una Goccia Onlus - Rome 23-25 May 2019***
- ***SCIENCE IN SERVICE OF LIFE - INTERNATIONAL CONGRESS* - Rzeszow - Polonia - 21-22 Giugno 2019**
- ***LIFE WELCOME AND PERINATAL HOSPICE - PRE- AND POST-NATAL THERAPEUTIC DEVELOPMENTS AND ACCOMPANIMENTATION PATHS FOR PATOLOGICAL PREGNANCY - Training Course - Rome - Policlinico Gemelli - April 27, 2019***
- ***SYNERGIES BETWEEN PRENATAL SCIENCE AND FAMILY ON THE PROBLEMS OF CONGENITAL FETAL ANOMALIES - Training Course - Rome - Policlinico Gemelli - April 28, 2018***
- ***FROM INFAUSED PRENATAL DIAGNOSIS TO PERINATAL HOSPICE - Conference - IRCCS Casa Sollievo della Sofferenza, San Giovanni Rotondo (Fg) - October 27,***


A New Holistic-Evolutive Approach to Pediatric Palliative Care
Carlo V. Bellieni
Springer

The bold wisdom of the great in face of the «impossible»

When you believe that it is impossible to do something....try not to disturb whoever is doing it !!

Albert Einstein



«They say this thing is impossible : then it can be done ! »

Armida Barelli **, co-founder with Agostino Gemelli of Catholic University**

Gemelli

Fondazione Policlinico Universitario Agostino Gemelli IRCCS
Università Cattolica del Sacro Cuore

HOSPICE PERINATALE
CENTRO PER LE CURE PALLIATIVE PRENATALI E POSTNATALI
S. MADRE TERESA DI CALCUTTA
POLICLINICO GEMELLI - ROMA

UNIVERSITÀ CATTOLICA del Sacro Cuore

Fondazione
Il Cuore in una Goccia

FONDAZIONE IL CUORE IN UNA GOCCIA -ETS

Fondazione
Il Cuore in una Goccia
Onlus

Thank you for your attention!