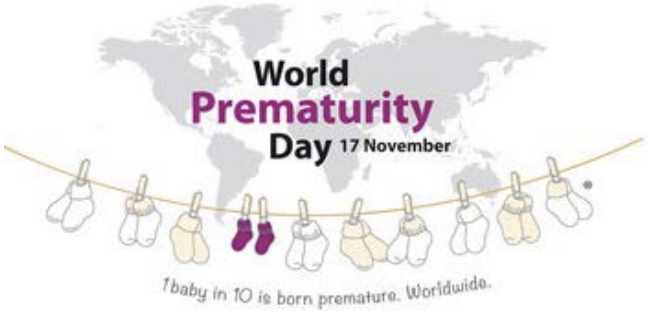
El recién nacido prematuro en el siglo XXI

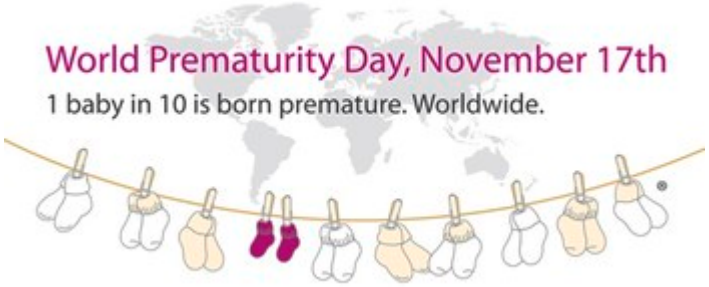
Ruth del Río

Servei Neonatologia. Sant Joan de Déu.
BCNatal – Centre de Medicina Maternofetal i Neonatologia de Barcelona
Hospital Sant Joan de Déu i Hospital Clínic
Universitat de Barcelona



CURSO INTERNACIONAL DE NEONATOLOGIA
Y MATRONERIA NEONATAL
PUERTO MONTT 10 Y 11 DE NOVIEMBRE 2017
AUDITORIO UNIVERSIDAD SAN SEBASTIAN - SEDE PATAGONIA

Ningún conflicto de interés…



En el Siglo XX …


The New York Times

MEN WALK ON MOON

ASTRONAUTS LAND ON PLAIN; COLLECT ROCKS, PLANT FLAG

Voice From Moon: 'Eagle Has Landed'

A Powdery Surface Is Closely Explored


“Soy vulnerable”

THE NURSLING

THE FEEDING AND HYGIENE OF PREMATURE & FULL-TERM INFANTS

BY

PIERRE BUDIN

PROFESSOR OF OBSTETRICS, UNIVERSITY OF PARIS; DIRECTOR OF THE CLINIQUE TARNIER; MEMBER OF THE ACADEMY OF MEDICINE

Authorised Translation

BY

WILLIAM J. MALONEY, M.B., Ch.B.

FELLOW OF THE OBSTETRICAL SOCIETY OF EDINBURGH; ETYLES SCHOLAR, HOULDSWORTH RESEARCH SCHOLAR, ETC.

WITH AN INTRODUCTION BY

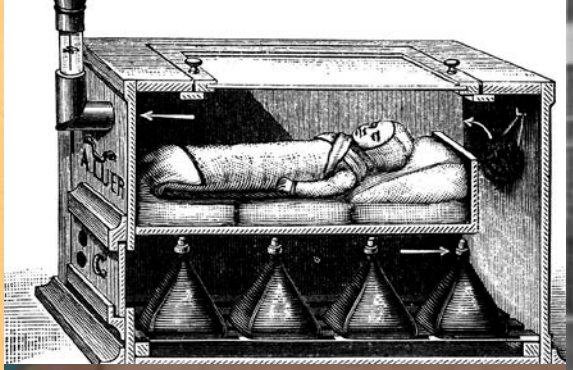
SIR ALEXANDER R. SIMPSON, M.D., LL.D., D.Sc.

EMERITUS PROFESSOR OF MIDWIFERY AND DISEASES OF WOMEN AND CHILDREN, UNIVERSITY OF EDINBURGH

ONE HUNDRED AND ELEVEN DIAGRAMS IN COLOUR AND OTHER ILLUSTRATIONS

LONDON

THE CAXTON PUBLISHING COMPANY



Couney at Chicago, 1933


The Detroit Free Press

NEW KENNEDY SON IS HIT BY BREATHING AILMENT

Baby Rushed To Specialists

Born 5½ Weeks Early; Named Patrick Bouvier

Officer Clear In Scott Case —Edwards

But Patrolman Is Taken Off Duty in Scout Cars

Auto Plunges Into River; Women Die

Invasion Crushed, Haiti Says

19 Nations Sign A-Ban Pact Today

British Journal of Obstetrics and Gynaecology
January 1990, Vol. 97, pp. 11–25

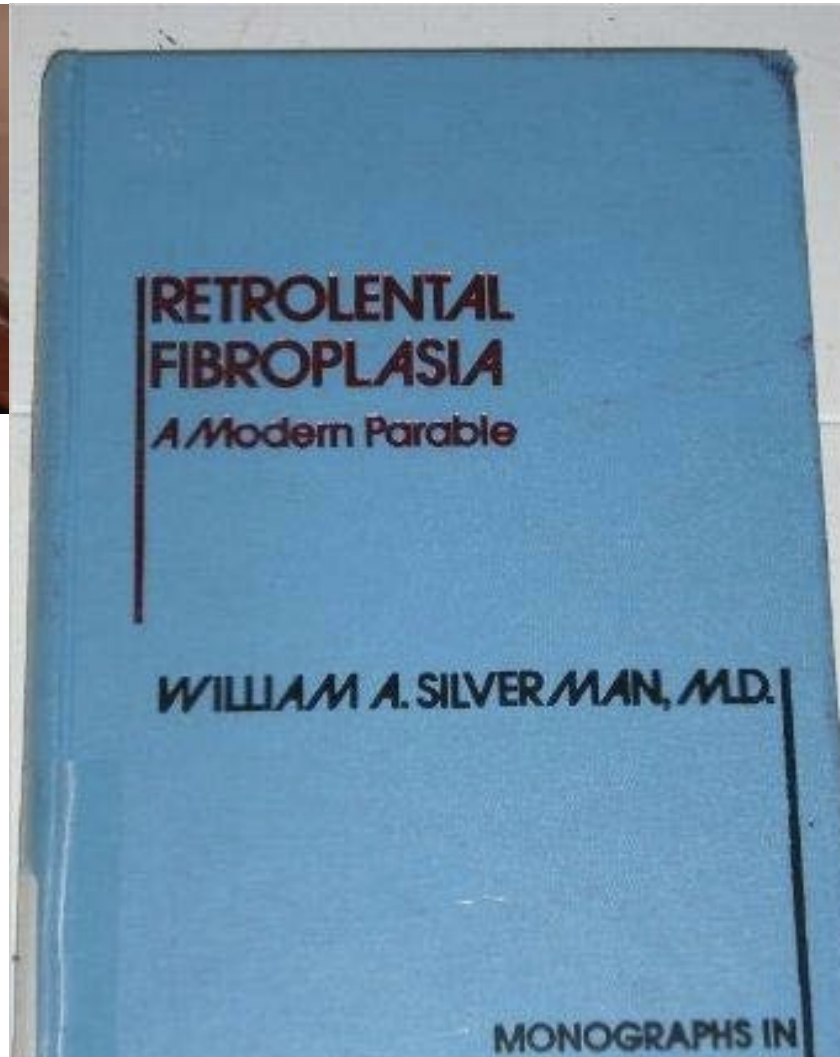
The effects of corticosteroid administration before preterm delivery: an overview of the evidence from controlled trials

PATRICIA CROWLEY, IAIN CHALMERS, MARC J. N. C. KEIRSE

Table 5. Effect of corticosteroids before preterm delivery on early neonatal deaths

Study	Treated *n*	Treated (%)	Control *n*	Control (%)	Odds ratios and 95% CI: Numerical
Liggins & Howie (1972)	36/532	(6·77)	60/538	(11·15)	0·58 (0·38–0·89)
Block *et al.* (1977)	1/69	(1·45)	5/61	(8·20)	0·22 (0·04–1·12)
Schutte *et al.* (1979)	3/64	(4·69)	12/58	(20·69)	0·23 (0·08–0·67)
Taeusch *et al.* (1979)	5/56	(8·93)	7/71	(9·86)	0·90 (0·27–2·96)
Doran *et al.* (1980)	2/81	(2·47)	10/63	(15·87)	0·18 (0·05–0·57)
Teramo *et al.* (1980)	0/38	(0·00)	0/42	(0·00)	1·00 (1·00–1·00)
Gamsu *et al.* (1989)	14/131	(10·69)	20/137	(14·60)	0·70 (0·34–1·44)
Collaborative Group (1981)	36/371	(9·70)	37/372	(9·95)	0·97 (0·60–1·58)
Morales *et al.* (1986)	7/121	(5·79)	13/124	(10·48)	0·54 (0·22–1·33)
Papageorgiou *et al.* (1979)	1/71	(1·41)	5/75	(6·67)	0·27 (0·05–1·36)
Morrison *et al.* (1978)	2/67	(2·99)	7/59	(11·86)	0·26 (0·07–1·03)
Schmidt *et al.* (1984)	5/34	(14·71)	5/31	(16·13)	0·90 (0·24–3·42)
Typical odds ratio					0·59 (0·47–0·75)

Odds ratios and 95% CI: Graphical — 0·1, 0·5, 1, 2, 10


RETROLENTAL FIBROPLASIA

A Modern Parable

WILLIAM A. SILVERMAN, M.D.

MONOGRAPHS IN

Rey-Martinez Kangaroo Mother Program: An Alternative Way of Caring for Low Birth Weight Infants? One Year Mortality in a Two Cohort Study

Nathalie Charpak, MD*; Juan G. Ruiz-Peláez, MD, MMedSci‡; and Yves Charpak MD, PhD§

Feature Endeavour Vol.33 No.2

From breast to bottle: a history of modern infant feeding

Linda Bryder

The History Department, The University of Auckland, Private Bag 92019, Auckland, 1142, New Zealand

don in the 1910s. Wellcome

Library, London.

El siglo XX…

FIGURE 1 Early 20th century demonstration of the gavage fe
ing technique for premature infants (Hess 1922).

En el HJSD…

El siglo XX…

En el HSJD… (sin comentarios)

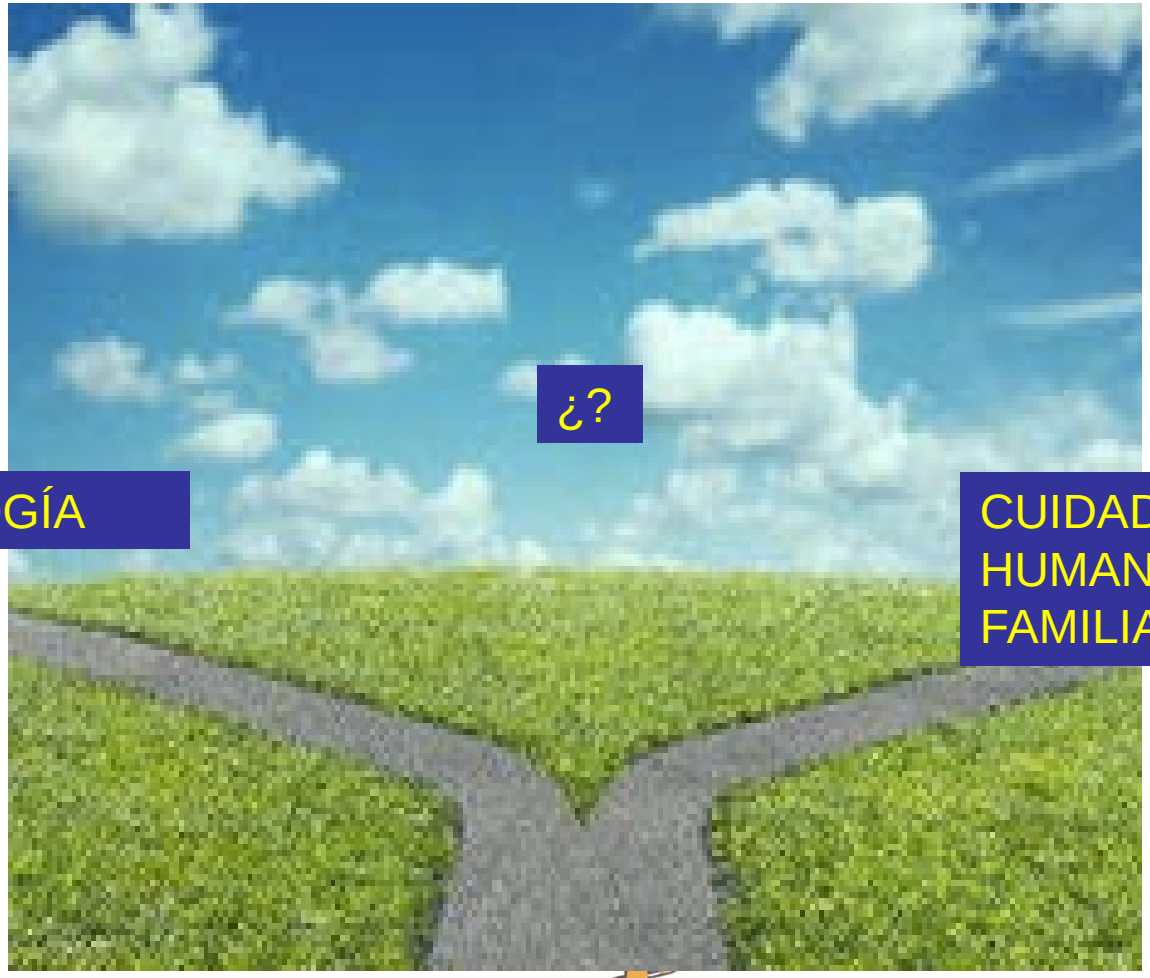
En el Siglo XXI …

-**Neonatólogo** 55 años: “la genética que ahora está empezando… y las células madre”

-**Enfermera neonatal**: “Más tecnología y menos tocar al niño”

-**Obstetricia:** “evitar que nazcan prematuros; tratar mejor la infección que nos trae de cabeza”

-**Madre de recién nacido prematuro**: “respetar al niño” “cuidados más humanizados”


¿?
TECNOLOGÍA
CUIDADOS MÁS HUMANIZADOS + FAMILIAS

En el siglo XXI…

1.TECNOLOGÍA

2.INVESTIGACIÓN CLÍNICA DE CALIDAD

3.GENÉTICA

4.RETOS (HEREDADOS DEL SIGLO XX)

5. FAMILIAS

1. En el siglo XXI, nuevas tecnologías…

A- Menos invasivas…

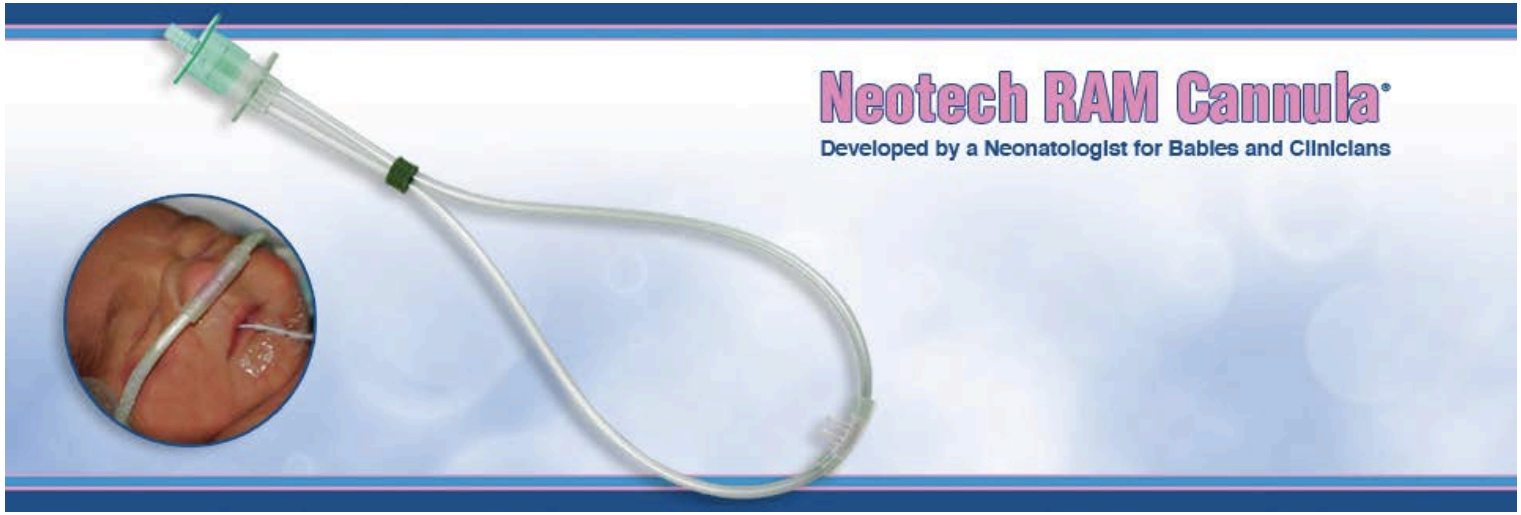
Menos invasivas…

Empleo GNAF HSJD 2006-2016, comparación con VON

Center 251 and Network Values
Respiratory Care - All VLBW Infants
High Flow Nasal Cannula
Birth Year

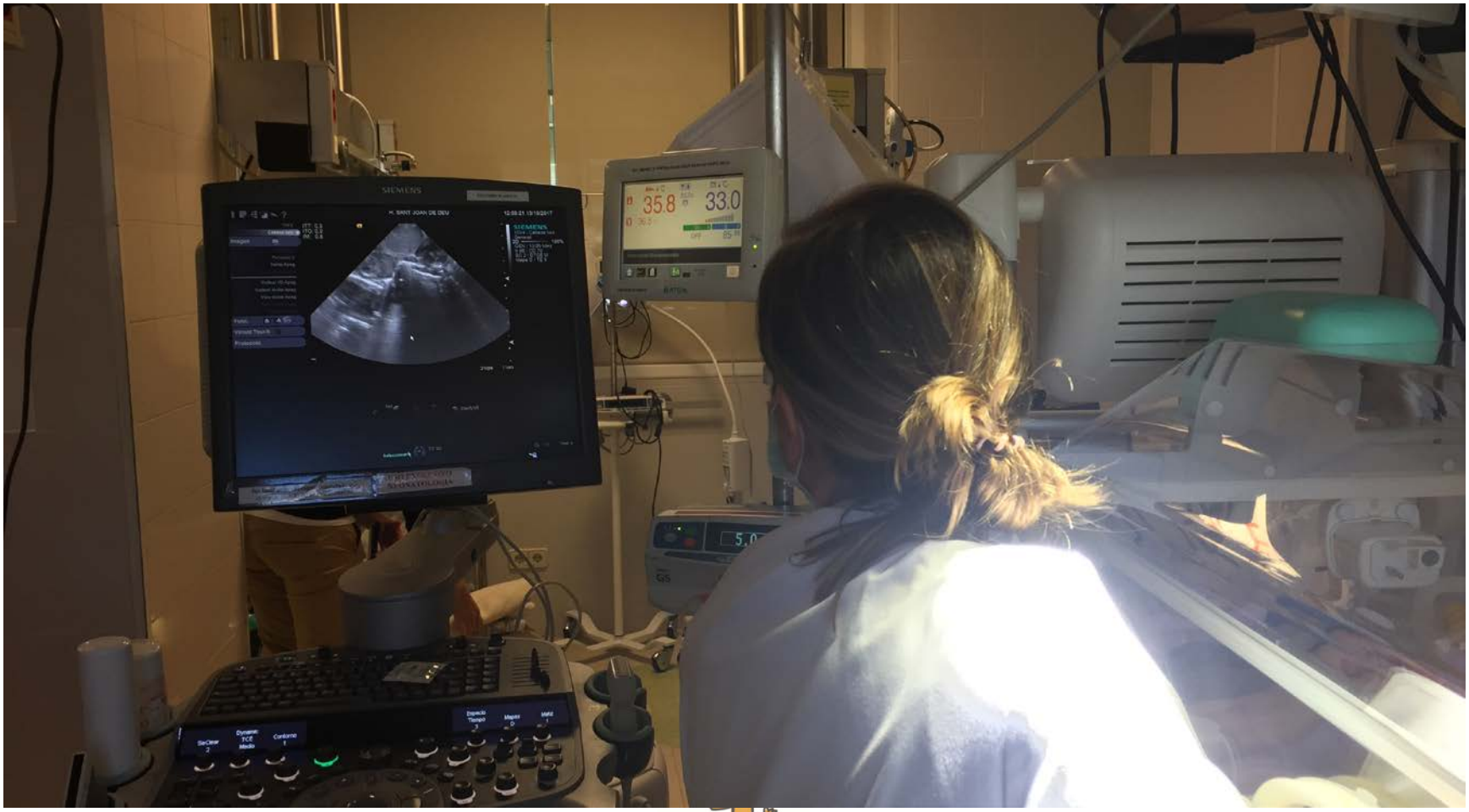
Birth	Center			Network		
	Cases	N	%	%	Q1	Q3
2006	0	93	0.0%	39.1%	5.9%	62.5%
2007	0	79	0.0%	44.5%	6.9%	66.2%
2008	14	98	14.3%	46.9%	9.3%	69.6%
2009	27	73	37.0%	48.1%	11.1%	72.2%
2010	30	72	41.7%	50.0%	10.9%	72.1%
2011	32	53	60.4%	51.2%	15.8%	73.8%
2012	40	84	47.6%	50.8%	18.2%	73.8%
2013	37	82	45.1%	51.4%	23.8%	73.5%
2014	34	62	54.8%	53.4%	27.0%	73.8%
2015	31	59	52.5%	52.7%	27.0%	73.7%
2016	46	66	69.7%	53.1%	27.7%	74.2%
All	319	856	37.3%	49.5%	18.2%	66.8%

Menos invasiva…

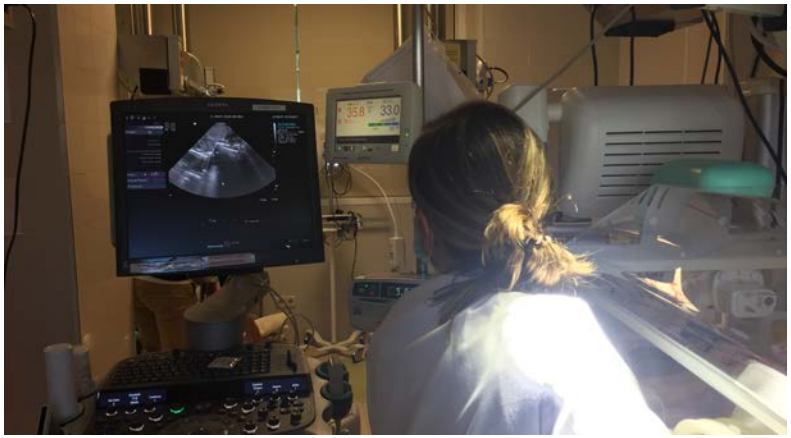


Cánulas RAM

Menos invasividad en el diagnóstico…



Menos invasividad en el diagnóstico…



- Ecografía pulmonar
- Ecocardiografía funcional
- Canalización de vías, punción lumbar
- Comprobación posición de catéteres

-Routine Ultrasonography in the neonataol intensive care unit. Chen et al. Medicine 2017; 90-92.
-Prospective investigations of a novel ultrasound assisted lumbar puncture technique. Gorn et al. Academic emergency medicine 2017;1.

Tecnología para la docencia-SIMULACIÓN

Sala de simulación Darwin, HSJD. Dra M Reyné

B-Tecnología para la docencia-SIMULACIÓN

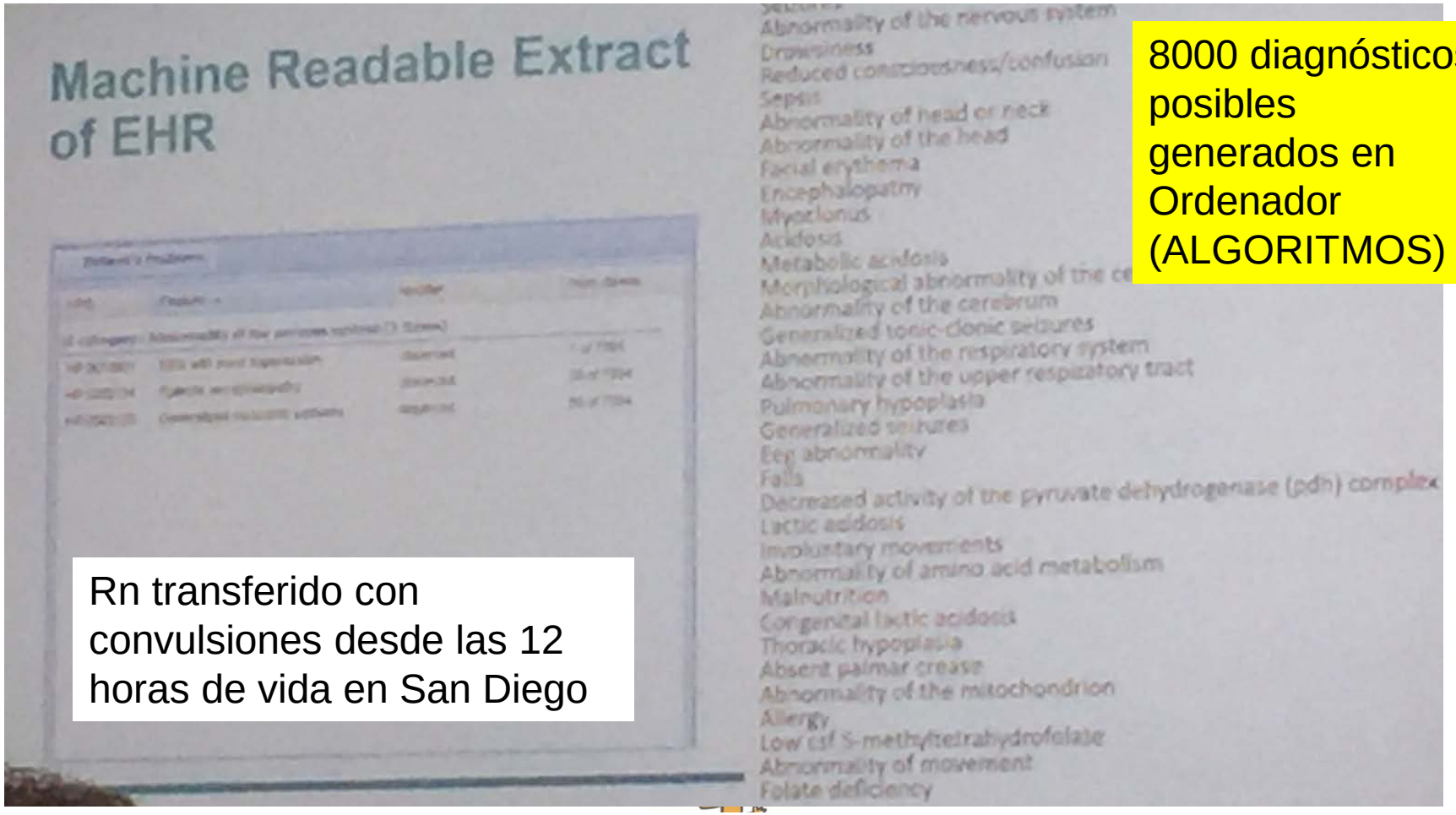
Sala de simulación
Darwin, HSJD

Dra M Reyné

B-Tecnología para probar espacios

Simulación HSJD

C- Tecnología en el diagnóstico



8000 diagnósticos posibles generados en Ordenador (ALGORITMOS)

Rn transferido con convulsiones desde las 12 horas de vida en San Diego

De Kingsmore, VON Annual Congress Chicago 2017

D-Tecnología-Telemedicina

Journal of Perinatology (2012) 32, 55–63

www.nature.com/jp

ORIGINAL ARTICLE

The use of mobile robotic telemedicine technology in the neonatal intensive care unit

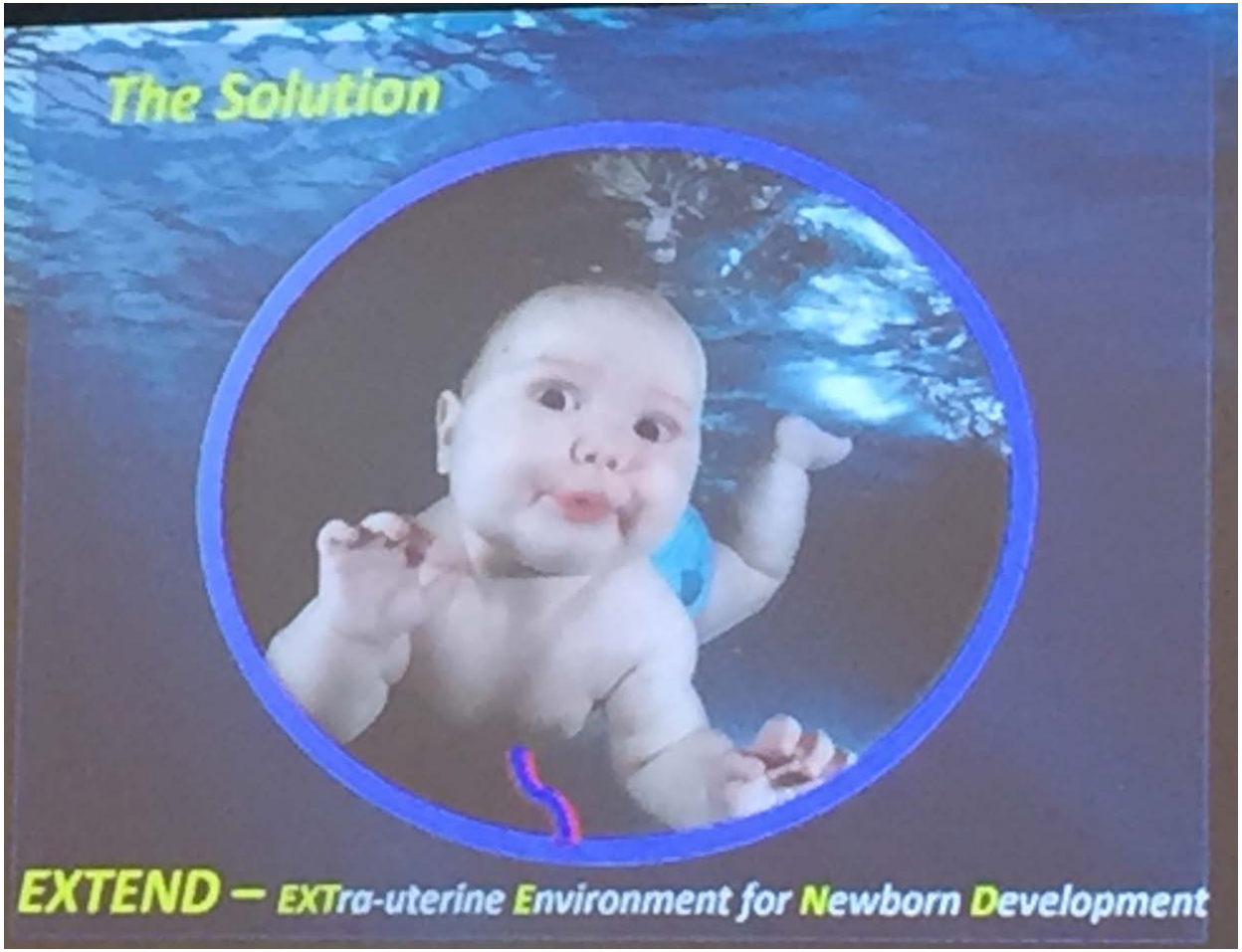
A Garingo[1,2], P Friedlich[1,2], L Tesoriero[1,2], S Patil[1,2], P Jackson[1,2] and I Seri[1,2]

[1]Center for Fetal and Neonatal Medicine and the USC Division of Neonatal Medicine, Children's Hospital Los Angeles, Los Angeles, CA, USA and [2]Department of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles, CA, USA

"Tele mentoring" desde centros más pequeños a centros de referencia… Pero también facilitando menos médicos dentro de las Unidades?

Figure 1 Telemedicine equipment (mobile robot) at patient's bedside. The robot is equipped with a pan-tilt-zoom head with a video camera, microphone, and liquid crystal display (LCD) screen and motorized platform and operates under the control of the physician at a remote site. The operator's face is projected on the screen creating a more human-type physical presence at the bedside. The operator's computer screen is also projected in the left lower corner of the screen of the robot, so that the bedside caregiver also sees what the operator of the robot is looking at on the screen of his/her station's computer at the remote site (see text for details).

Tecnología de ciencia ficción?



De Flake, VON Annual Congress Chicago 2017

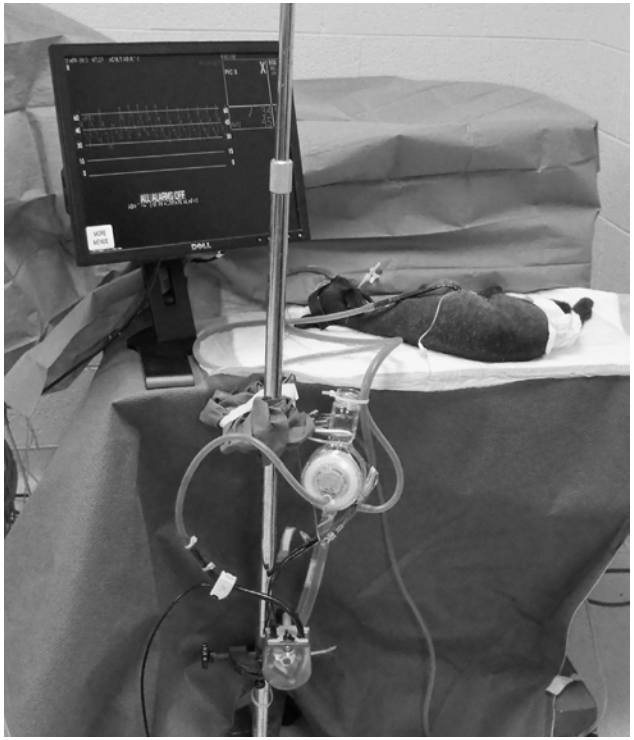
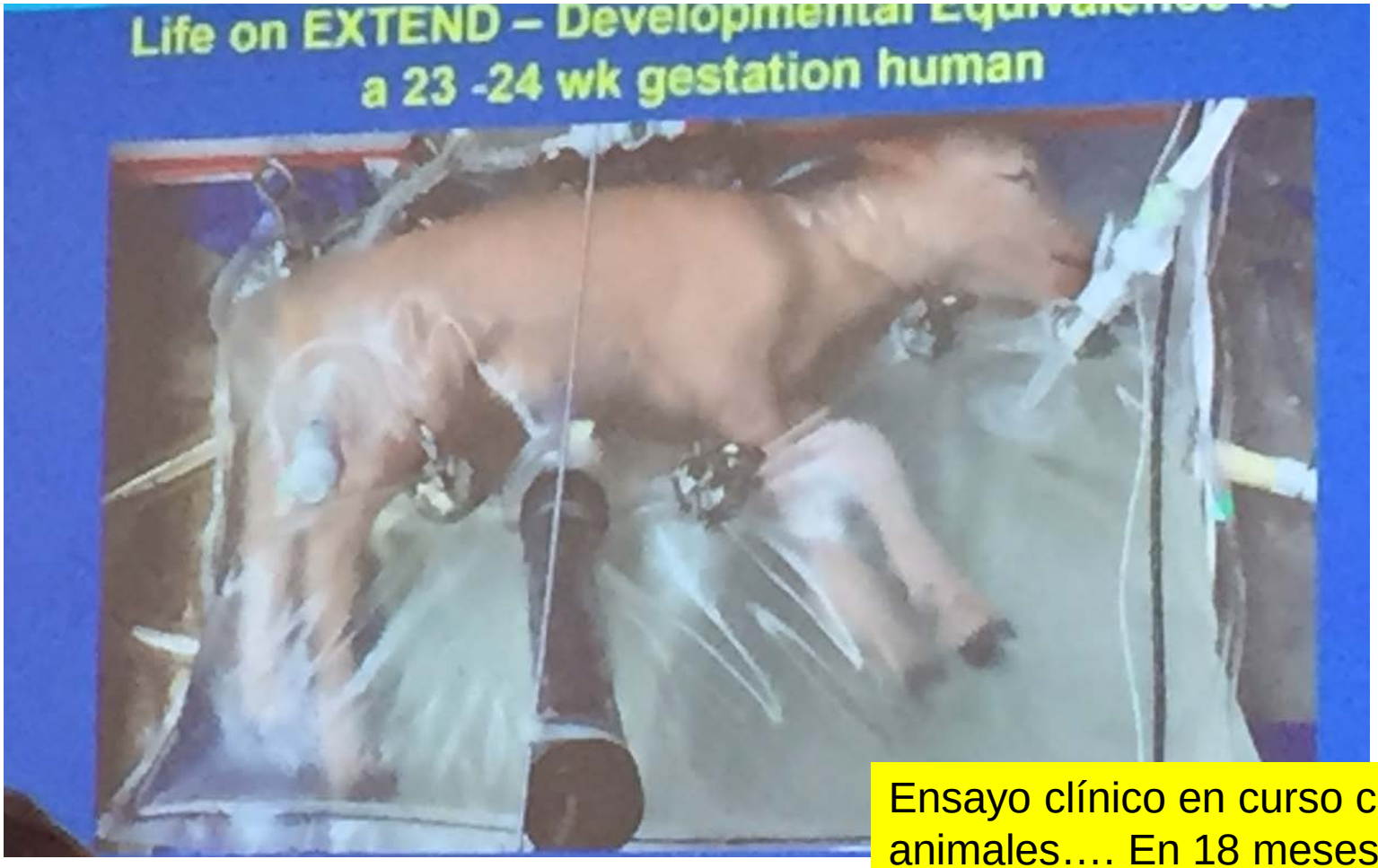


Fig. 2 – Premature lamb on artificial placenta (consisting of pump, gas exchange device, heat exchanger, and blood pressure monitor).

Brave new world of Fetal Therapy. Extrauterine incubation as a bridge to viability in sheep. A Flake



Ensayo clínico en curso con animales…. En 18 meses en humanos.

GRETA

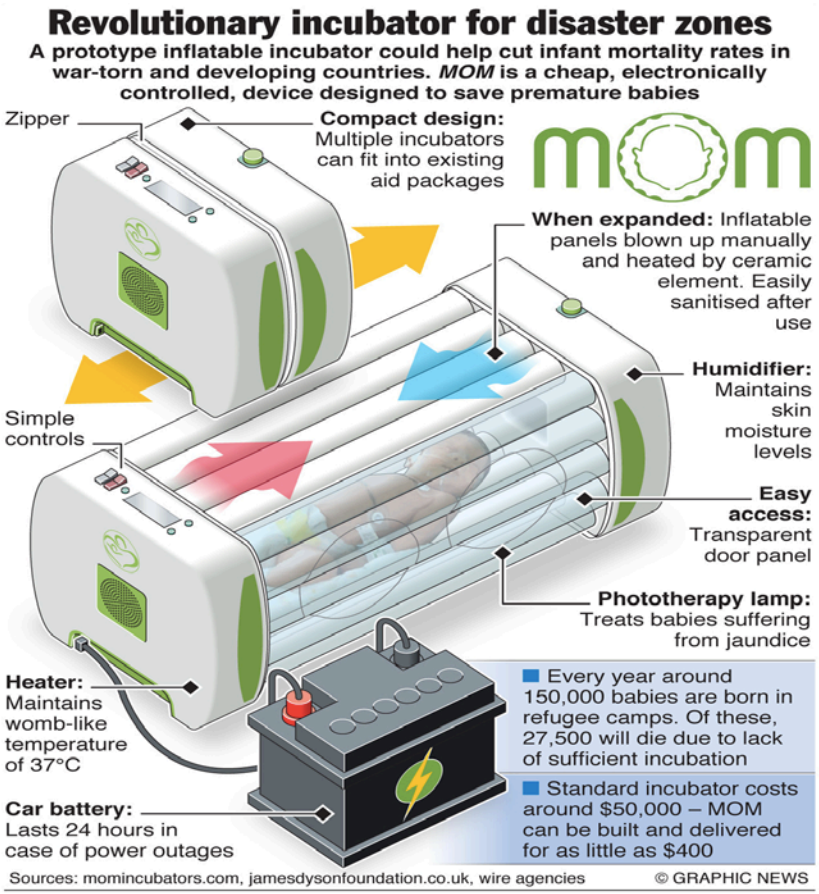
Brave new world of Fetal Therapy. Extrauterine incubation as a bridge to viability in sheep. A Flake

-Intención es como puente entre el útero materno y la vida extrauterina desde las 23-24 semanas … 1 mes

Brave new world of Fetal Therapy. Extrauterine incubation as a bridge to viability in sheep. A Flake

- https://youtu.be/MbgHbYXs3cM

F- Tecnología accesible a todos



MOM INCUBATOR…
plegable… 400 euros!

2. Investigación clínica , calidad asistencial, seguridad del paciente

THE INFLUENCE OF THE THERMAL ENVIRONMENT UPON THE SURVIVAL OF NEWLY BORN PREMATURE INFANTS

William A. Silverman, John W. Fertig and Agnes P. Berger

Pediatrics 1958;22;876

LES 879

"hypothermic" controls.

Seventy-six of the ninety-one infants who were placed in "normothermic" incubators survived the trial period (83.5%). Sixty-two of the "hypothermic" infants survived the trial (68.1%). The data for the various weight groups are given in Table III. Adjustment of these survival rates simultaneously for the disparity in the position or route of delivery and age on admission left them practically unaltered (83.3% vs. 68.5%): A simultaneous classification of the two tempera-

-Intento de realizar un ensayo clínico

-Sobres sellados para los diferentes pesos, se les asigna durante 5 días ambiente "frío-Tº incubadora 28,7ºC" o "normotérmico-Tª incubadora 31,9ªC" …y ven resultados

2. Investigación clínica , calidad asistencial, seguridad del paciente

THE INFLUENCE OF THE THERMAL ENVIRONMENT UPON THE SURVIVAL OF NEWLY BORN PREMATURE INFANTS

William A. Silverman, John W. Fertig and Agnes P. Berger

Pediatrics 1958;22;876

TABLE III

SURVIVAL RATES BY BIRTHWEIGHT GROUPS

Birthweight	*Number of Infants*	*Survival Rate* "*Normothermic*" *Incubator* (%)	"*Hypothermic*" *Incubator* (%)
1,501+ gm	84	92.9	78.6
1,001–1,500 gm	70	85.7	77.1
<1,001 gm	28	50	14.3

In each birthweight category survival was greater among infants in "normothermic" incubators.

Sant Joan de Déu

2. Investigación clínica y calidad asistencial

Vermont Oxford NETWORK

Center 251 and Network Values
Admissions and Discharges - All VLBW Infants
Admissions - Number of Admissions
Birth Year

	Center	Network
Birth Year	Cases	N
1990	0	2,955
1991	0	3,868
1992	0	5,033
1993	0	6,629
1994	0	8,364
1995	0	10,892
1996	0	15,274
1997	0	20,451
1998	0	24,696
1999	0	27,456
2000	0	30,469
2001	0	31,49
2002	86	33,666
2003	87	36,647
2004	97	40,949
2005	86	46,216
2006	96	50,278
2007	81	54,163
2008	98	57,335
2009	77	58,492
2010	72	57,743
2011	57	59,385
2012	88	59,735
2013	87	60,87
2014	62	61,251
2015	60	62,493
2016	67	64,007
All	1,236	990,807

Sant Joan de Déu

The EPICure Study: Outcomes to Discharge From Hospital for Infants Born at the Threshold of Viability

Kate Costeloe, FRCP, FRCPCH*; Enid Hennessy, MSc‡; Alan T. Gibson, PhD, FRCP, FRCPCH§; Neil Marlow, DM, FRCP, FRCPCH‖; and Andrew R. Wilkinson, FRCP, FRCPCH¶, for the EPICure Study Group

TABLE 5. Markers of Condition Over First 12 Hours and Use of Surfactant Therapy

Gestation Completed Weeks	Heart Rate <100 bpm 5 Minutes After Birth		Admission Temperature °C			CRIB Score (9)		Surfactant Therapy		
	Number Positive/ Number Reporting	%	*n*	Median IQR	% Below 35°C	*n*	Median IQR	Number Receiving/ Number Reporting	%	% of Those Treated Receiving Animal-Derived Surfactant
21	2/3	66.7	3	32.0	66.7	2	13, 17	2/3	66.7	50.0
22	5/21	23.8	20	34.0 33.4–34.8	80.0	20	14 11–17	16/22	72.7	75.0
23	23/125	18.4	120	34.5 33.5–35.6	58.3	111	13 11–17	102/131	77.9	54.9
24	33/291	11.3	279	35.0 34.1–35.8	42.7	276	12 9–15	259/296	87.5	57.5
25	51/344	14.9	335	35.3 34.8–36.0	29.6	329	8 5–11	303/351	85.4	58.9
Total	114/783	14.6	757	35.0 34.1–35.9	40.4	738	11 8–			

-4004 recién nacidos en UK e Irlanda entre marzo 1995 y Diciembre 1995 entre 20 y 25 semanas EG. 811 ingresan en UCIN

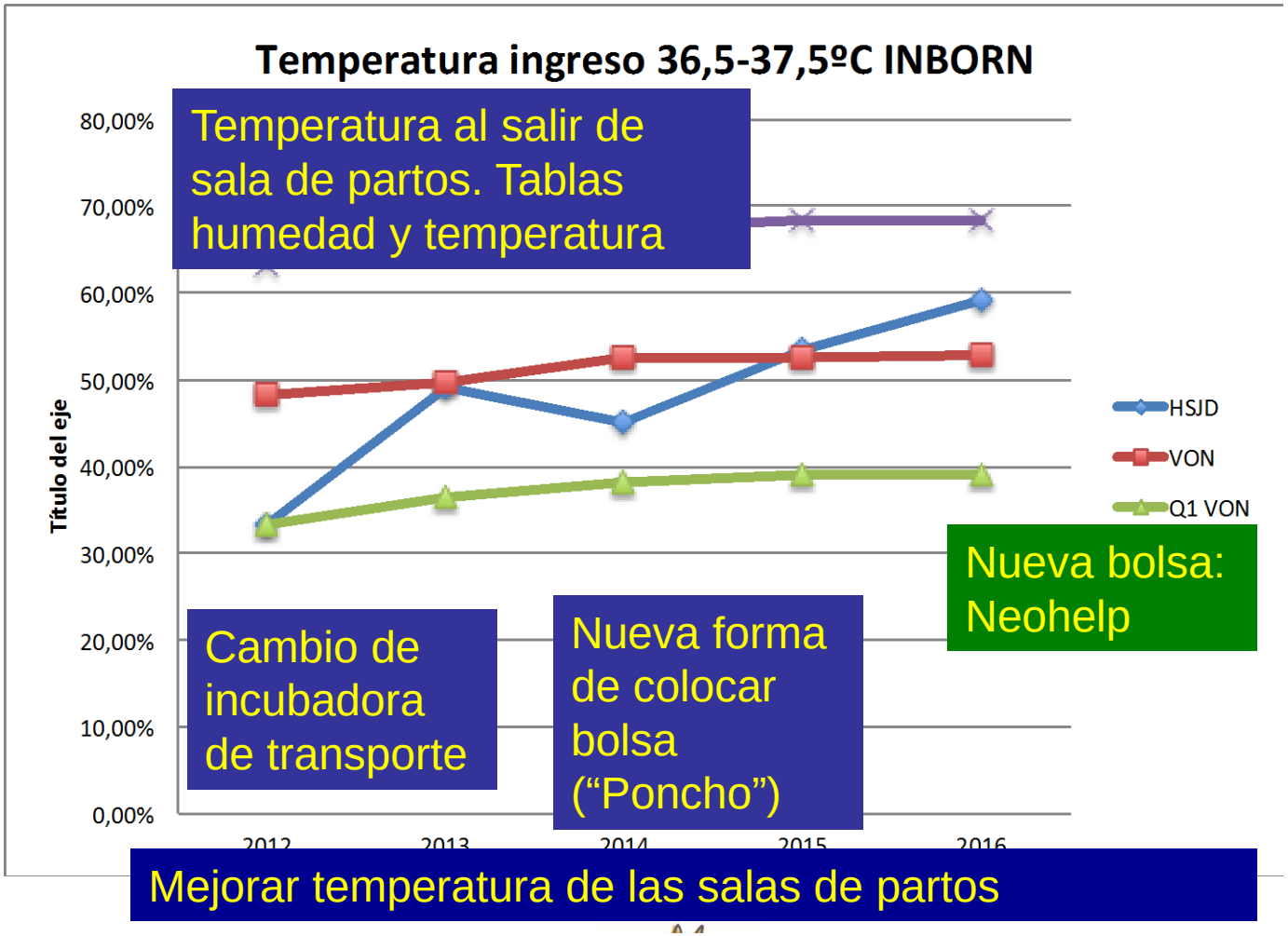
TABLE 9. Results of Univariate and Multivariate Analyses of Factors Associated With Death Before Discharge

Variable (All Yes/No Unless Stated)	(*n*)	Univariate Analysis		Multivariate Analysis (Variables Known at Birth) *n* = 781		Multivariate Analysis (All Variables) *n* = 712	
		OR (95% CI)	*P* Value	OR (95% CI)	*P* Value	OR (95% CI)	*P* Value
Known at birth							
Gestation (per wk)	(811)	.47 (.38–.57)	<.0005	.47 (.38–.58)	<.0005		
Birth weight (per 100 g)	(811)	.60 (.53–.68)	<.0005				
Birth weight for gestation (per 100 g)	(811)	.68 (.59–.79)	<.0005	.68 (.58–.79)	<.0005		
Multiple	(811)	1.39 (1.01–1.90)	.044	1.55 (1.08–2.22)	.018		
Male sex							.008
Any obstetric problems							
Preeclampsia							
PROM (>24 h)							
Cervical suture	(798)	.57 (.34–.97)	.040				
APH	(798)	1.33 (.97–1.84)	.081				
Chorioamnionitis	(798)	.47 (.33–.68)	<.0005	.49 (.32–.73)	.001	.51 (.32–.82)	.005
Antenatal steroid	(800)	.38 (.28–.53)	<.0005	.50 (.35–.73)	<.0005	.57 (.38–.85)	.006
Tocolytics	(792)	.57 (.41–.79)	.001	.66 (.45–.97)	.034		
Maternal age (per y)	(801)	.98 (.96–1.01)	.460				
Ethnic group = white	(811)	1.13 (.81–1.59)	.130				
Postnatal variables							
Cesarean vs vaginal delivery	(805)	1.07 (.73–1.58)	.720				
HR at 5 min <100 bpm	(811)	3.21 (1.95–5.28)	<.0005			1.99 (1.07–3.67)	.029
Admission temperature ≥35°C	(757)	.31 (.23–.43)	<.0005			.58 (.39–.85)	.006
CRIB score (per point; 9)	(738)	1.35 (1.29–1.42)	<.0005			1.31 (1.25–1.38)	<.0005
Postnatal transfer	(804)	1.32 (.87–2.01)	.190				
Surfactant therapy	(811)	.95 (.64–1.41)	.790				

Aumento de mortlidad de 28% por cada grado de temperatura MENOS al ingreso!!!

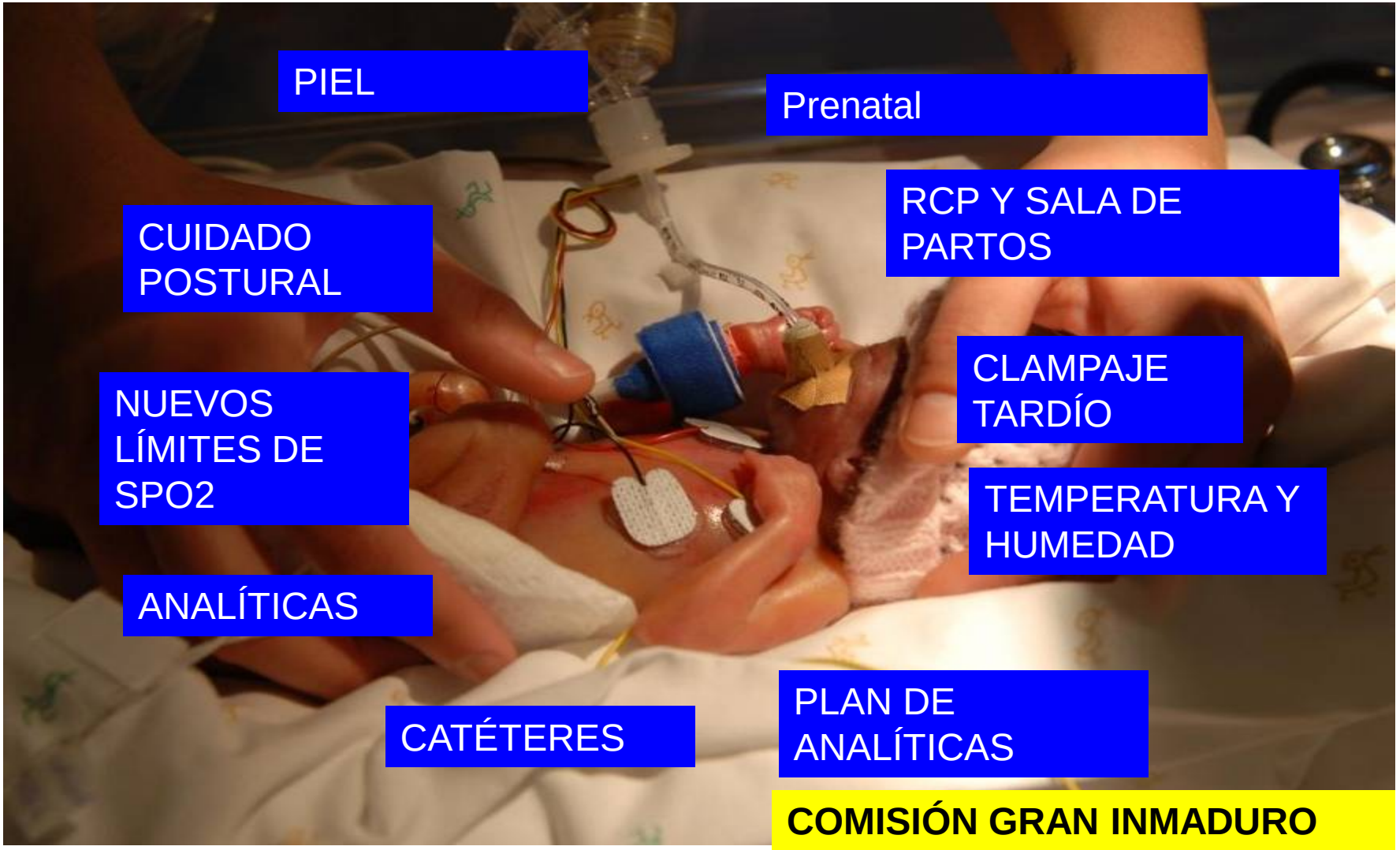
OR indicates odds ratio of dying; APH, antepartum hemorrhage.

El caso de la temperatura de ingreso



Grupo Temperatura: C Baquero, R Alfaro, G Torres, I Caperote, E Blanco, C Corral. Grupo poncho: C Collazos, E Lamonja, S Egea, I Casal.

PROYECTO DE MEJORÍA DE TRATAMIENTO Y CUIDADOS EN LAS PRIMERAS 72 HORAS



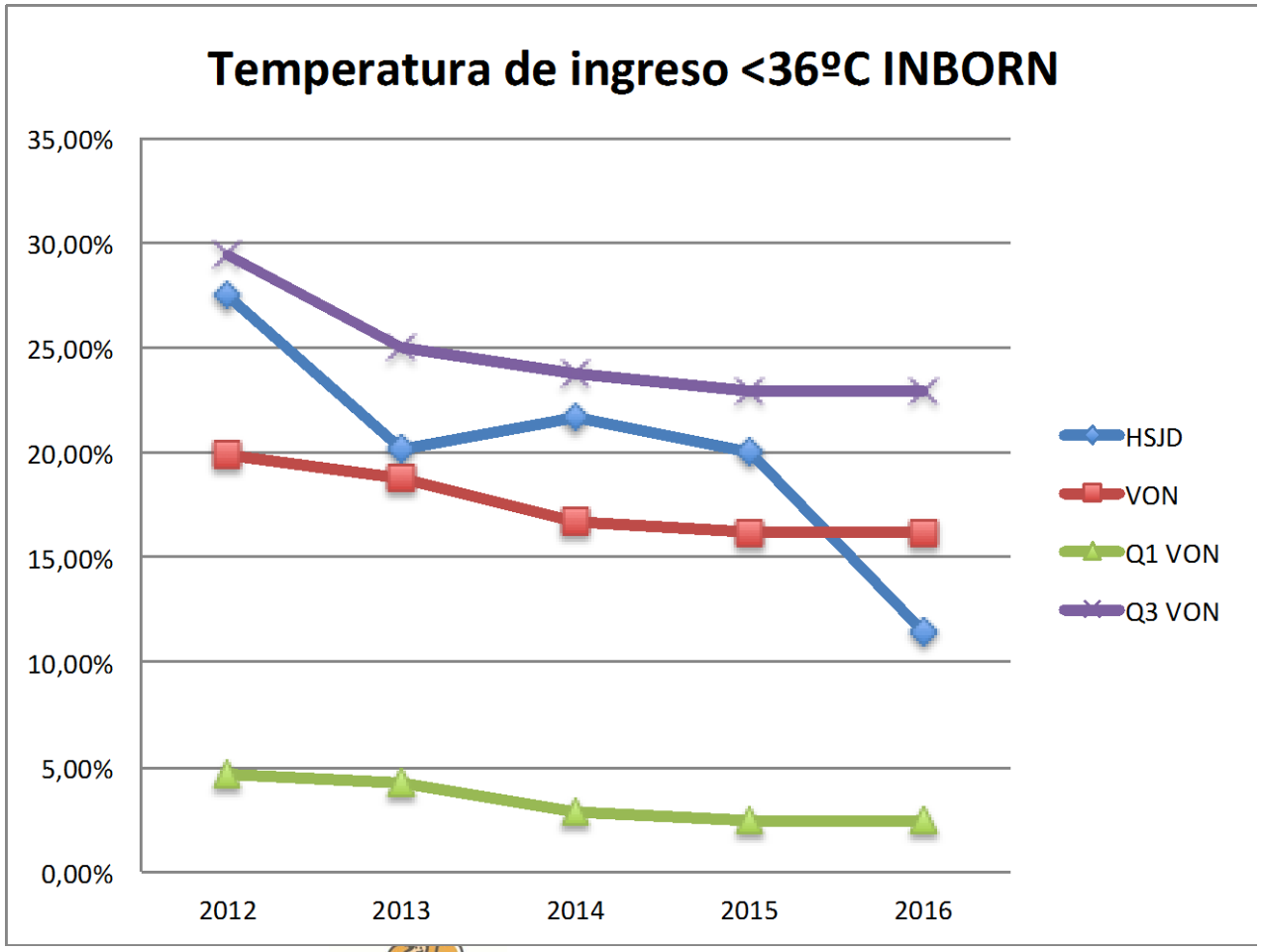
PROYECTO DE MEJORÍA DE TRATAMIENTO Y CUIDADOS EN LAS PRIMERAS 72 HORAS

EL SIGLO XXI NECESITA EQUIPOS CLÍNICOS MULTIDISCIPLINARES IMPLICADOS EN LA MEJORÍA CONCRETA DE LOS PROBLEMAS REALES

El caso de la temperatura de ingreso

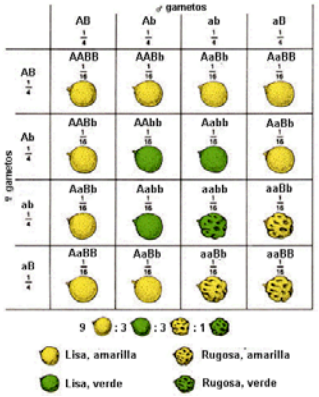
CUESTA
MUCHO
BAJAR UN PORCENTAJE...

PERO MERECE LA PENA

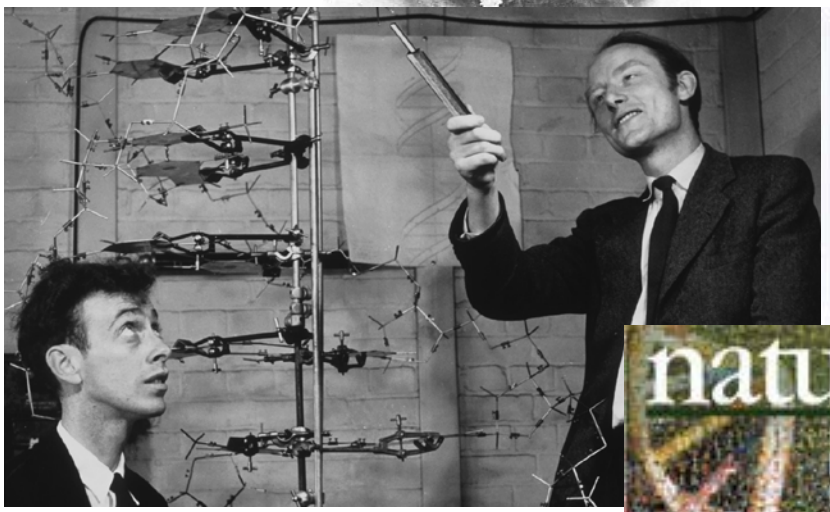


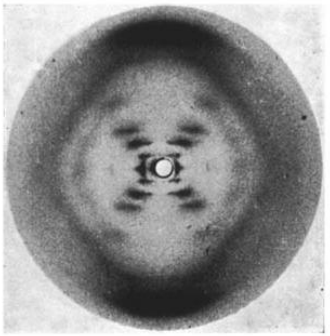
2. Genética

1860



1950





1980

2000

1953, secuencia de DNA identificada
2003, Se completa proyecto Genoma humano
2053, ????

2.Genética

Cariotipo

↓

Microarray (resolución 10-30kb)

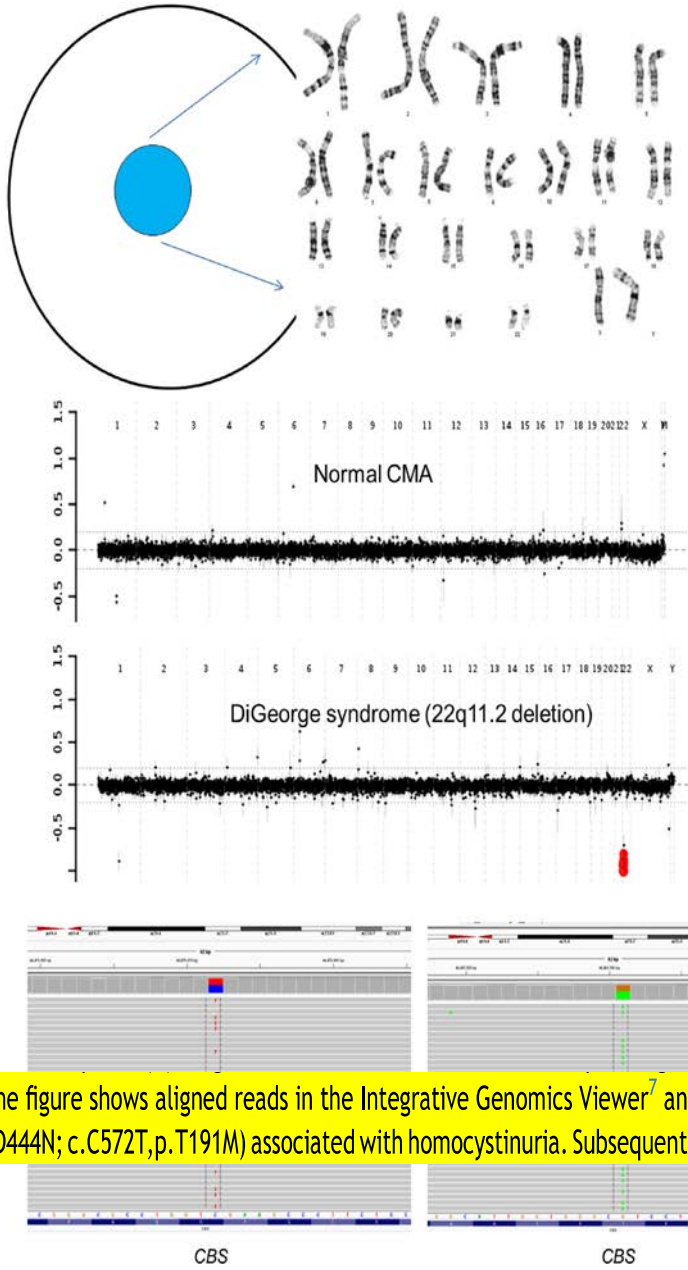
↓

Exoma (180000 exones)

↓

Genoma completo

Hallazgos de alteraciones con significación desconocida



hg19 with a previously described analysis pipeline.[6] The figure shows aligned reads in the Integrative Genomics Viewer[7] and demonstrates two heterozygous variants in *CBS* (c.G1330A, p.D444N; c.C572T,p.T191M) associated with homocystinuria. Subsequently, Sanger

2.Genética

Cariotipo

↓

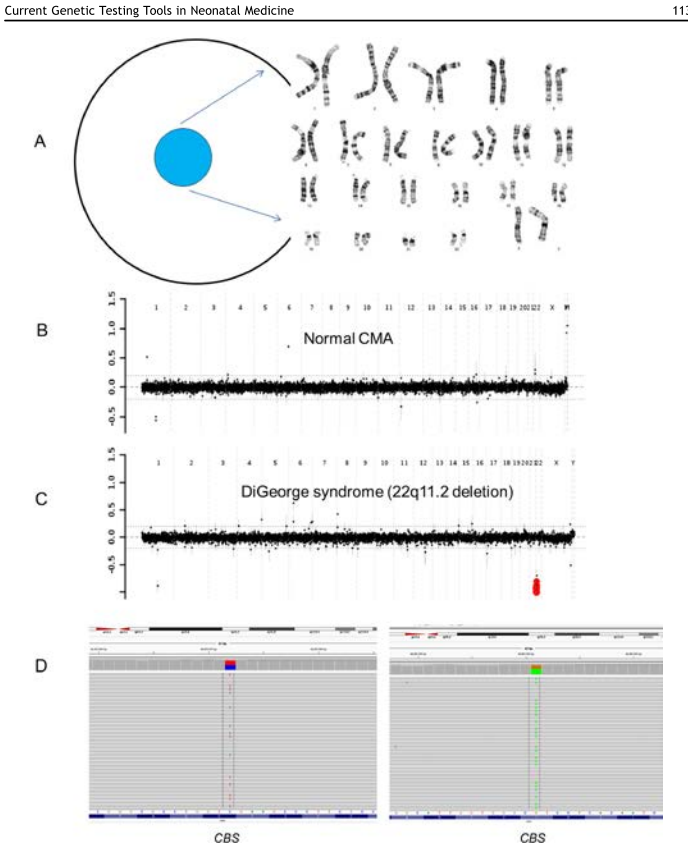
Microarray (resolución 10-30kb)

↓

Exoma (180000 exones)

↓

Genoma completo



FASCINANTE…PERO NECESIDAD DE UNA FORMACIÓN ESPECÍFICA

Genoma humano-3 billones de nucleótidos

Locus: posición en un cromosoma

Alelo:variación en un gen en un cierto locus

Single Nucleotide polimorphism-SNP

Variant of Unknwon Significance-VUS

Copy number variant-CNV

Genome Wide association-GWAS

Genomas múltiples… MICROBIOMA-GENOMA

) 623–631

BOX 1: PRECISION MEDICAL MANAGEMENT FOLLOWING RAPID GENETIC DISEASE DIAGNOSIS IN THE NICU

1. Psychosocial benefits for parents (answers, knowledge of prognosis, planning, psychological and religious support).
2. Precision treatments for affected infants that prevent death, diminish disease severity, delay progression or improve quality of life.
4. Earlier avoidance of futile or painful treatments, unnecessary or invasive testing, and planning of withdrawal of care.
5. Time to plan and implement investigative new treatments.
6. Basis for increased coordination of care among providers.
7. Genetic counseling regarding recurrence risk.
8. Parental referral to specific support groups.
9. Reduced lifetime cost of care.

ase diagnosis in the NICU.

edicine.

"MEDICINA DE PRECISIÓN" ….

TIME

Genetic Testing Is Providing New Hope for Babies Born with Mysterious Ailments

Time Magazine, 21 Sept 2017

-Convulsiones neonatales… genoma completo…Diagnóstico de Sd de Otahara con una mutación de novo en 68 horas (**Rady Children´s hospital, San Diego)**

-Cambian tto a CBZ y Fenitoína con resultado

4. Células madre

Mesenchymal Stromal Cell Therapy in Bronchopulmonary Dysplasia: Systematic Review and Meta-Analysis of Preclinical Studies

STEM CELLS TRANSLATIONAL MEDICINE 2017;00:00–00 www.StemCellsTM.com

Alveolarization Subgroup Analyses	SMD	(C.I.)	# of Exps
Dose			
Low <=100,000 cells (I^2 = 76.9 %, p < .01)	-1.50	(-2.29, -0.72)	8
Mid 100,001 - 999,999 cells (I^2 = 48.44 %, p < .01)	-1.52	(-2.04, -0.99)	15
High >1,000,000 cells (I^2 = 72.98 %, p < .01)	-0.86	(-1.72, -0.01)	10
Route			
Intranasal (I^2 = 5.76 %, p < .36)	0.28	(-0.43, 1.00)	4
Intraperitoneal (I^2 = 30.8 %, p < .22)	-0.72	(-1.28, -0.16)	5
Intratracheal (I^2 = 59.8 %, p < .01)	-1.62	(-2.09, -1.15)	19
Intravenous (I^2 = 83.31 %, p < .01)	-2.23	(-3.65, -0.81)	5
Source			
Bone Marrow (I^2 = 78.2 %, p < .01)	-1.47	(-2.22, -0.72)	15
Umbilical Cord (I^2 = 55.74 %, p < .01)	-1.21	(-1.63, -0.78)	18
Treatment Timing			
<=P5 (I^2 = 67.02 %, p < .01)	-1.13	(-1.58, -0.67)	22
>P5 (I^2 = 73.73 %, p < .01)	-1.82	(-2.61, -1.03)	11
Assessment Timing			
<=P14 (I^2 = 57.41 %, p < .01)	-1.08	(-1.51, -0.65)	17
P15-P28 (I^2 = 80.97 %, p < .01)	-2.24	(-3.62, -0.85)	7
>P28 (I^2 = 70.88 %, p < .01)	-1.30	(-2.10, -0.51)	9

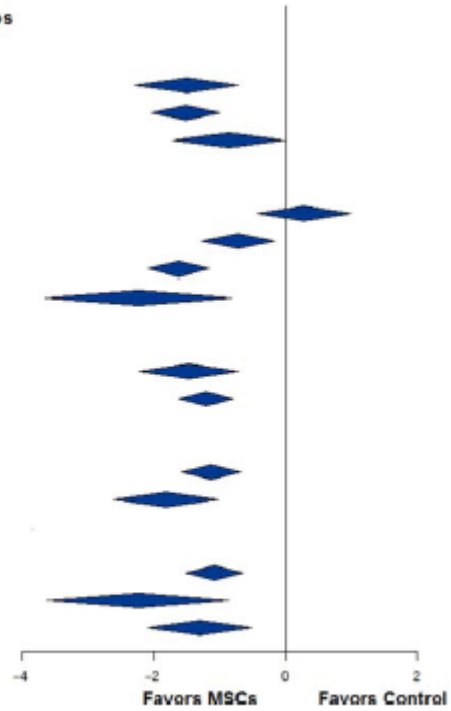


Figure 4. Subgroup analyses of MSCs in animal model of bronchopulmonary dysplasia for the primary outcome of alveolarization. Abbrevi
MSC, mesenchymal stromal cells; SMD, standardized mean difference.

-Modelos animales de DBP (Ratones)

-Mejor IV que IT

-No efectos adversos referidos

-Efectos tanto de MSC como el empleo de su medio de cultivo en **alveolarización,inflamación, HTP y angiogénesis**

4. Células madre

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY REVIEW

Editor's Choice

Repair of neonatal brain injury: bringing stem cell-based therapy into clinical practice

NIENKE WAGENAAR[1] | CORA H NIJBOER[2] | FRANK VAN BEL[1]

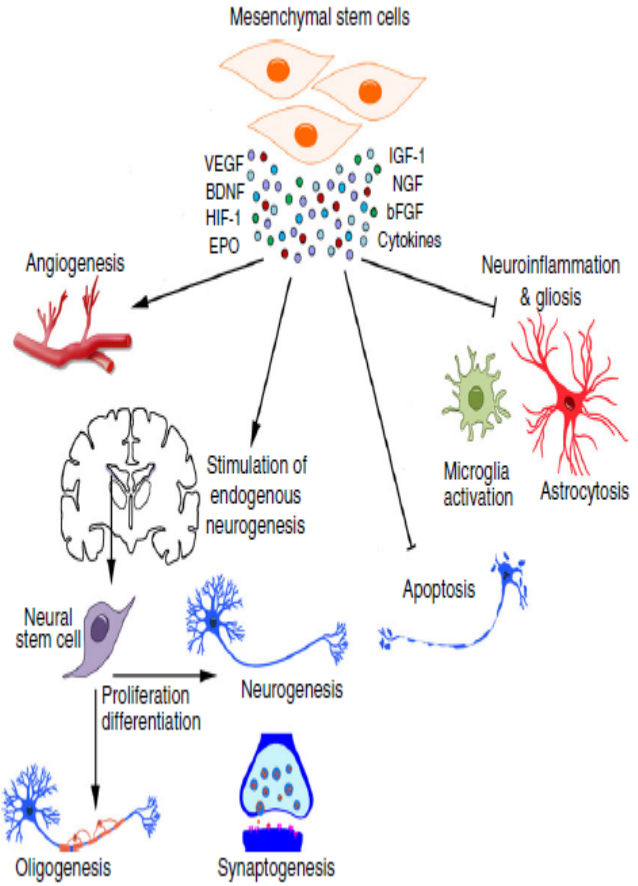
Developmental Medicine & Child Neurology 2017, 59: 997–1003

-Administración sistémica o local (inyección directa, intranasal) Dosis depende de vía de administración

-Ventana para efectividad elevada (en estudios animales hasta 10 días después de hipoxia isquemia)

-Efectos adversos (neoplasias) No en modelos animales neonatales ni en adultos

-Estudios en curso para HIE, infarto, HIV, hidrocefalia…)



5. Retos (heredados del siglo XX)

5. Retos-resistencia a antimicrobianos

Bad Bugs, No Drugs: No ESKAPE! An Update from the Infectious Diseases Society of America

Helen W. Boucher,[1] George H. Talbot,[2] John S. Bradley,[3,4] John E. Edwards, Jr,[5,6,7] David Gilbert,[8] Louis B. Rice,[9,10] Michael Scheld,[11] Brad Spellberg,[5,6,7] and John Bartlett[12]

INTERNACIONAL

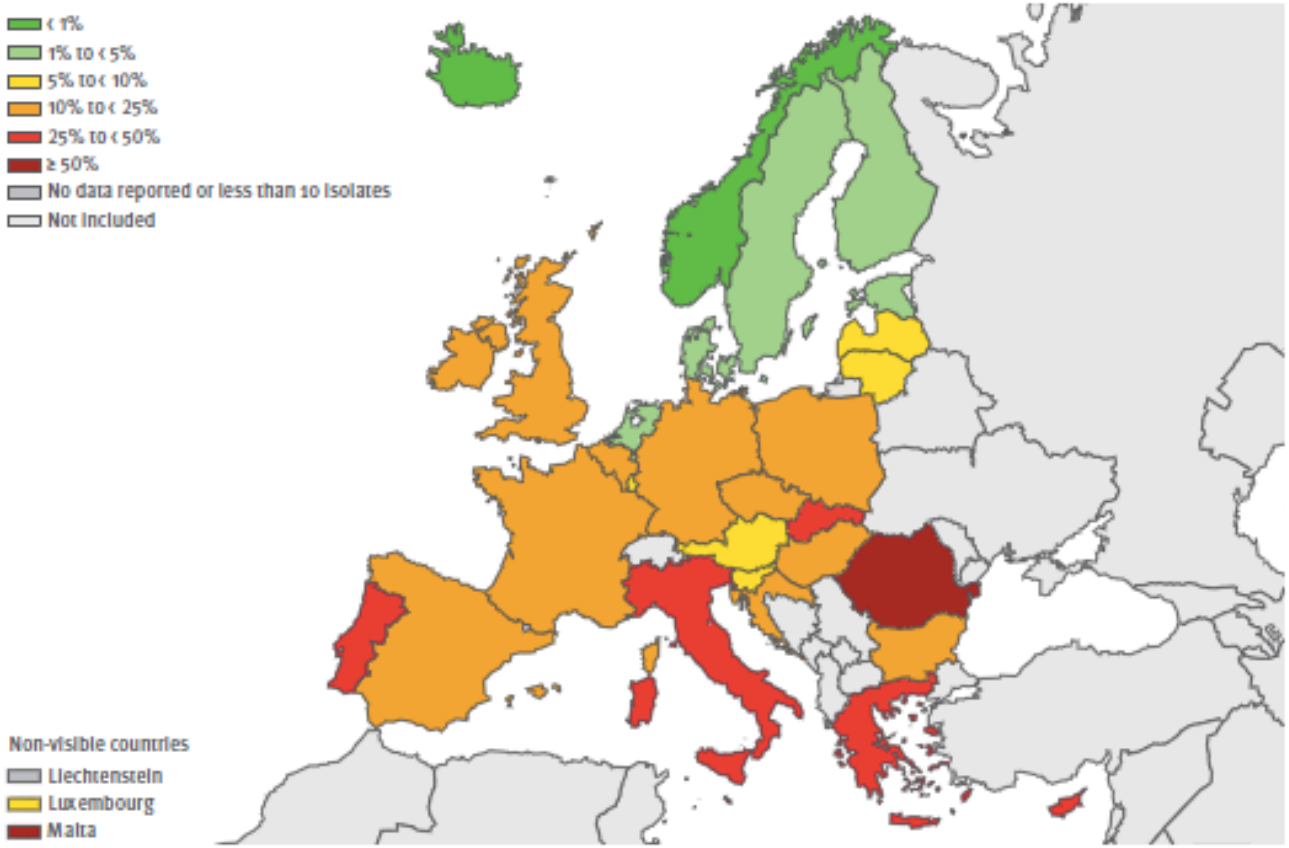
EUROPA EE UU MÉXICO AMÉRICA LATINA ORIENTE PRÓXIMO ASIA ÁFRICA FOTOS OPINIÓN BLOGS TITULARES »

Una mujer muere en EE UU por una bacteria resistente "a todo"

La septuagenaria había sido ingresada en India varias veces antes de volver a su país

Diferencias de resistencias a antimicrobianos en los diferentes países

Figure 3.23. *Staphylococcus aureus*. Percentage (%) of invasive isolates resistant to meticillin (MRSA), by country, EU/EEA countries, 2013



Resistencias a antimicrobianos

- Mayoría de **antibióticos prescritos en un país los reciben los animales**… (70-80%)
  - Para promocionar crecimiento
  - Para evitar contagio de infecciones (aglomeración en granjas)
- Problema GLOBAL político-sanitario

Resistencia a AB e industria

The global challenge of new classes of antibacterial agents: an industry perspective
Prabhavathi Fernandes

Current Opinion in Pharmacology 2015, 24:7–11

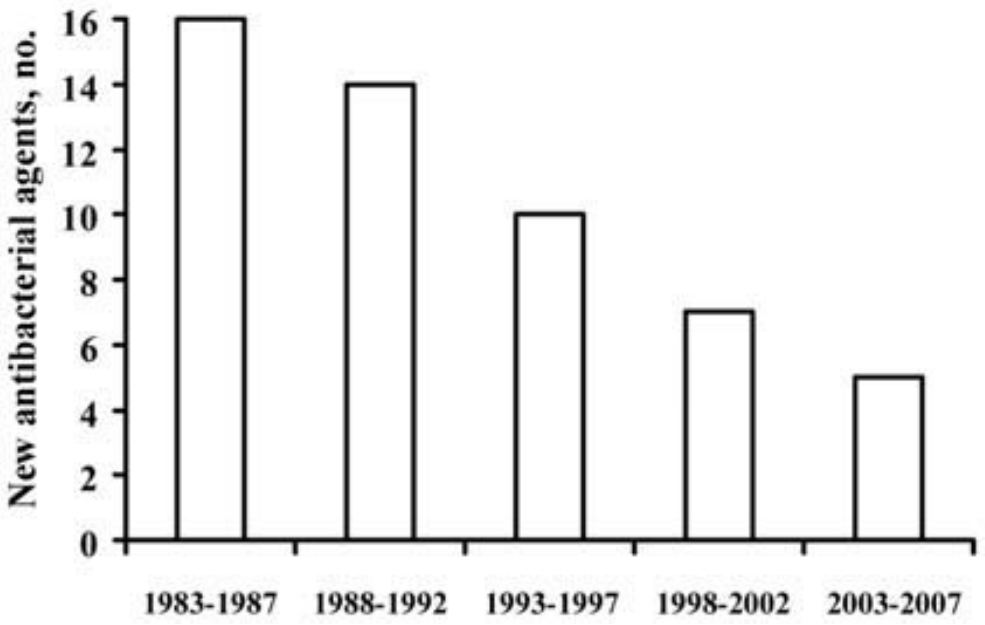
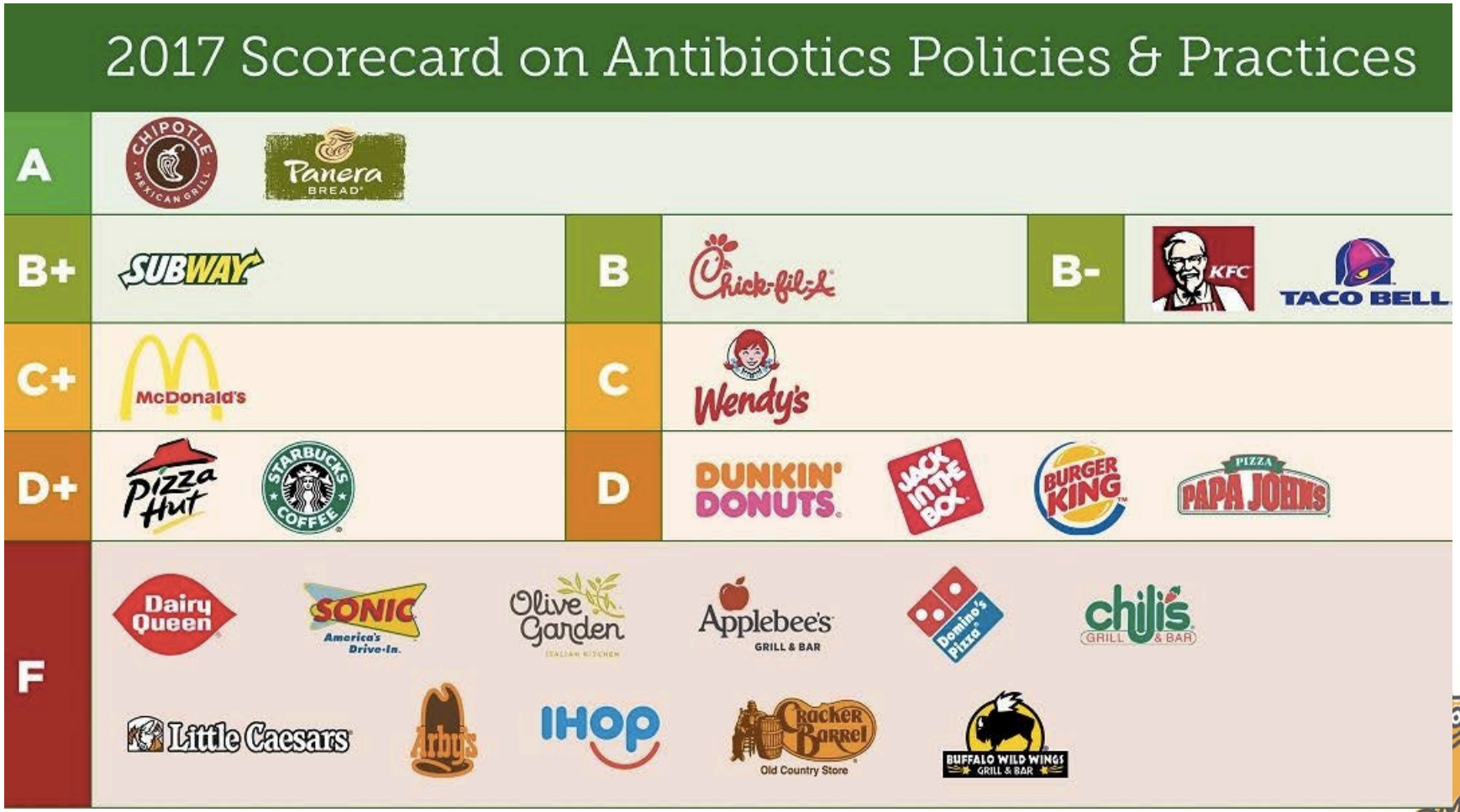


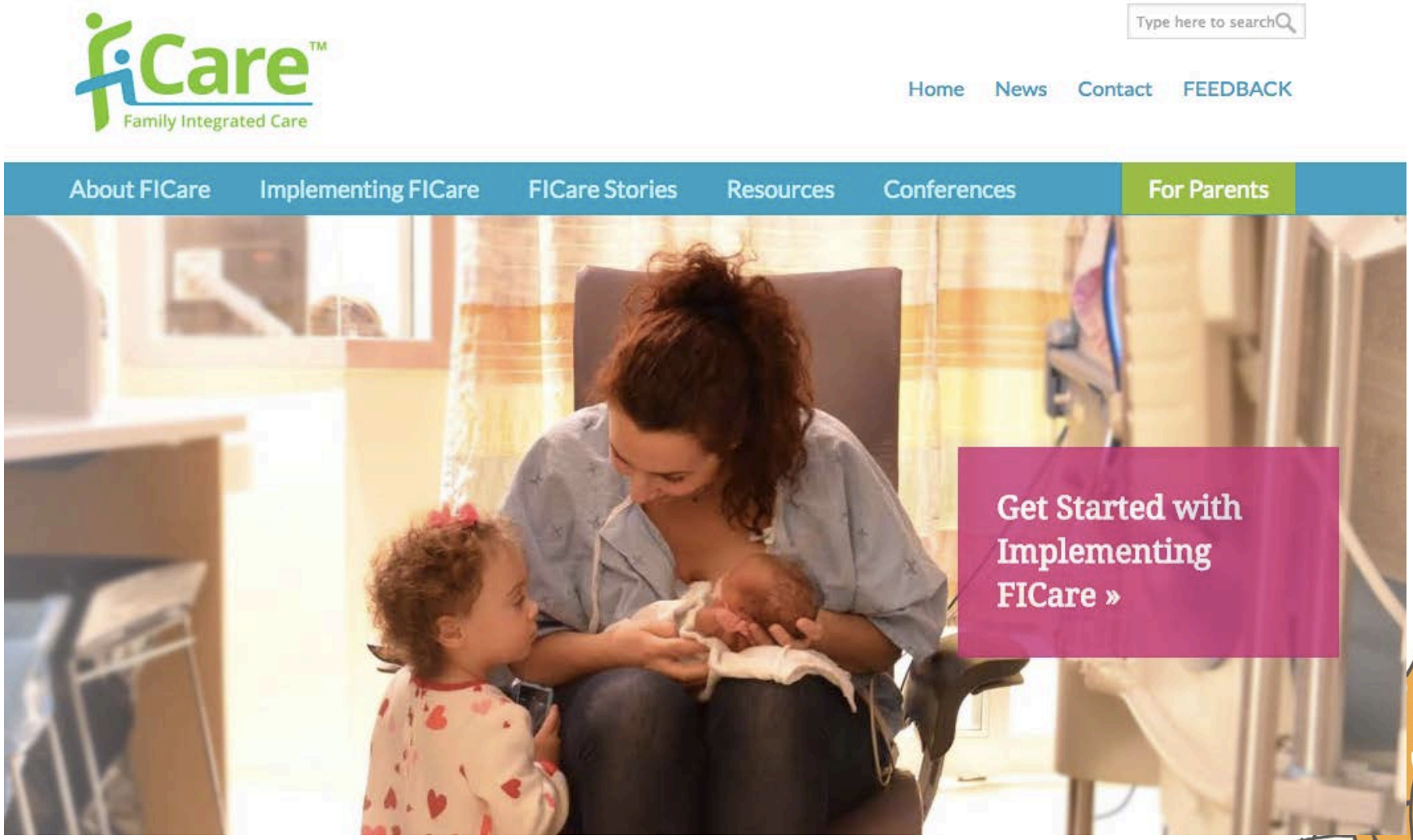
Figure 1. New antibacterial agents approved in the United States, 1983–2007, per 5-year period [2, 3].

Resistencia a antimicrobianos: qué hacer como consumidores…



De J Newland, VON Annual Congress Chicago 2017

6. Las familias INTEGRADAS en la Unidad



6. Las familias INTEGRADAS en la Unidad

The Mother-Infant Unit at Tallinn Children's Hospital, Estonia: A Truly Baby-Friendly Unit

Adik Levin, MD, PhD

40

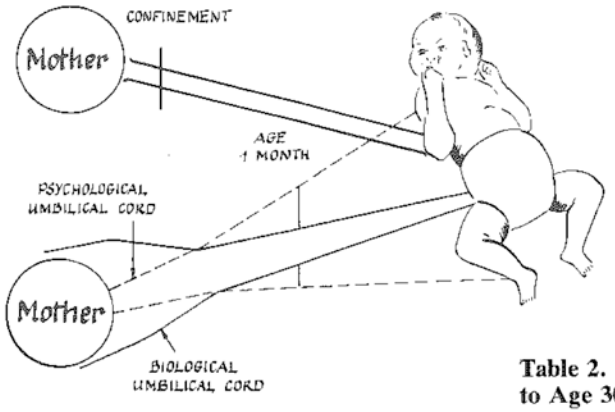


Fig. 1. Schematic representation of the c tween the baby and mother after delivery.

Table 2. Weight Gain in Preterm Infants Cared for by Mothers and Nurses from Admission to Age 30 Days by Birth Order

	Weight Gain (Gm) From Admission to Age 20 Days			*Weight Gain (Gm) From Age 20–30 Days*			*Weight Gain (Gm) From Admission to Age 30 Days*		
	Primary Caregiver			*Primary Caregiver*			*Primary Caregiver*		
	Mother	*Nurse*	*p*	*Mother*	*Nurse*	*p*	*Mother*	*Nurse*	*p*
1st child in family	322.7* (20.79)† (n = 19)	235.7 (29.7) (n = 19)	<0.01	455.0 (18.8) (n = 19)	249.6 (23.7) (n = 19)	<0.001	769.6 (20.9) (n = 19)	490.7 (34.5) (n = 19)	<0.001
2nd child in family	423.6 (33.2) (n = 20)	234.9 (35.6) (n = 11)	<0.001	353.6 (30.8) (n = 20)	204.8 (55.2) (n = 11)	<0.001	763.4 (42.7) (n = 20)	438.4 (51.9) (n = 11)	<0.001

* *Mean.*
† *Standard deviation.*

- **Lee “Changing the paradigm for improving neonatal care” FAMILY INTEGRATED CARE**

-Estudio piloto, marzo 2011. FAMILIA INTEGRADA en la Unidad neonatal. Enfermería “entrena” las competencias de los padres siguiendo un programa estructurado

-Prospectivo, caso control. 12 meses

-40 casos, 80 controles pareados. 4 camas dentro de la UCIN

-Padres tenían que estar al menos 8 horas/día

-Inclusión: menos 35 semanas con soporte respiratorio “bajo” (CPAP o menos). Exclusión: paliativos, pacientes inestables, críticos…

RESEARCH Open Access

A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit

Karel O'Brien[1,2*], Marianne Bracht[2], Kristy Macdonell[2], Tammy McBride[2], Kate Robson[2], Lori O'Leary[2], Kristen Christie[2], Mary Galarza[2], Tenzin Dicky[2], Adik Levin[3], Shoo K Lee[2,4]

O'Brien et al. BMC Pregnancy and Childbirth 2013, 13(Suppl 1):S12
http://www.biomedcentral.com/1471-2393/13/S1/S12

Outcomes

Infant Outcomes	FICare group Mean (sd)	Controls Mean (sd)	P-value
Zwt21-Zwt 1 Discharge weight gain	0.61(0.44) 25% ⇧	0.49(0.41)	0.26 <0.05
21 day wt gain (g/kg/day)	21.6 (6.4) 9% ⇧	20.3 (6.6)	0.48
Breastfeeding	85% ⇧	42%	<0.05
Nosocomial infection	0 ⇩	6(9.7%)	0.59
ROP	0 ⇩	8(14.3%)	<0.05
Incident reports Per 1000 patient days	0.84 25% ⇩	1.15	0.73

MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex

De S K Lee, **ESPR 2015 Budapest**

-Padres con Ficare: Menos ROP, menos infección nosocomial,más lactancia materna

- También menos estrés parental (escala PSS)

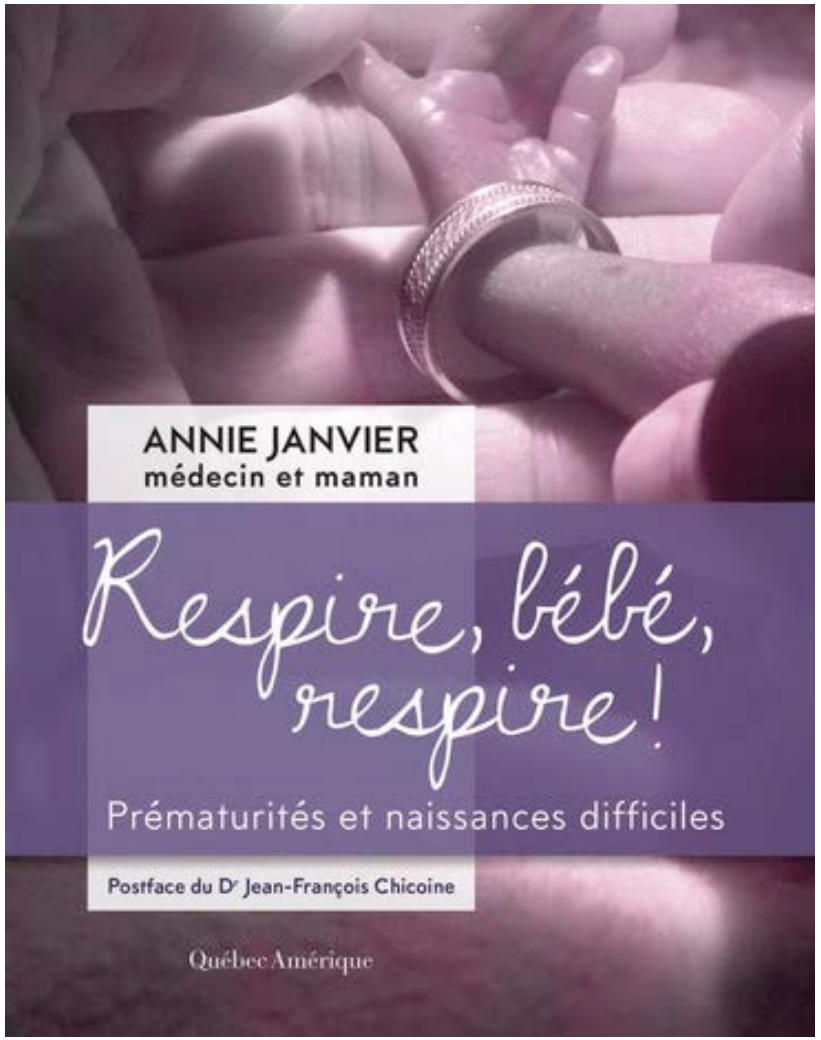
sant Joan de Déu
HOSPITAL MATERNOINFANTIL - UNIVERSITAT DE BARCELONA

B- Familias en nuevos espacios…

"Nosotros damos forma a los edificios y más tarde ellos nos dan forma a nosotros"

W Churchill, ex-prematuro

… C- Familias que son la parte fundamental de la UCIN



A DIFFERENT VIEW

Term MRI for small preterm babies: do parents really want to know and why has nobody asked them?

Rebecca Pearce, Jason Baardsnes (jason.baardsnes@cnrc-nrc.gc.ca)

Life Sciences, NRC Human Health Therapeutics Portfolio, National Research Council Canada, Montréal, QC, Canada

-" Maren fue dada de alta del hospital con 4 meses de vida. Durante el primer año estábamos petrificados e hipervigilantes …. Miraba a los ojos? Cogía cosas? Mostraba signos de ataxia…??"

"La RM de Maren no nos dio ninguna información sobre como es hoy --- sólo sirvió para aterrorizarnos"

Mareen tiene ahora 2 años y ninguna discapacidad…Sabemos que pueden aparecer alteraciones en su desarrollo posterior pero ninguna RM podría predecir este tipo de alteraciones.

-Mirando nuestra experiencia creemos que los padres deberían recibir un consentimiento informado antes de realizar una RM. Si los médicos creen que necesitan la información derivada de la RM, los padres deben poder elegir si quieren o no conocer esta información…"

Received

11 June 2012; accepted 15 June 2012.

Las familias integradas en la Unidad

-Apoyando a otras familias

-Integradas en los proyectos de mejoría de calidad asistencia

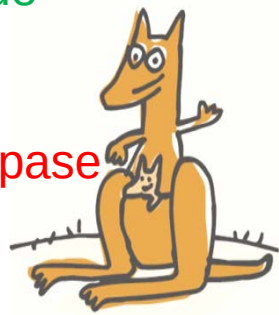
-En los **pases de visita**

Parental presence on neonatal intensive care unit clinical bedside rounds: randomised trial and focus group discussion

Mohamed E Abdel-Latif,[1,2] Danette Boswell,[1] Margaret Broom,[1] Judith Smith,[1] Deborah Davis[3,4]

Abdel-Latif ME, *et al*. *Arch Dis Child Fetal Neonatal Ed* 2015;**100**:F203–F209. doi:10.1136/archdischild-2014-306724

-"Comprenden mejor problemas del niño"
-"Derecho a estar presentes"
-"Refuerza su papel de padres"
-Confidencialidad
-Labor educativa del pase de visita (residentes)



ORIGINAL ARTICLE

Views of parents and health-care providers regarding parental presence at bedside rounds in a neonatal intensive care unit

MJ Grzyb[1,2], H Coo[1], L Rühland[1] and K Dow[1,2]

Journal of Perinatology (2014) 34, 143–148

www.nature.com/jp

Table 2. Views of parents who attended bedside rounds at least once during their child's stay in the Neonatal Intensive Care Unit ($n = 64$)

Statement	n *(%)*				
	Strongly agree	*Somewhat agree*	*Neutral*	*Somewhat disagree*	*Strongly disagree*
I liked being present during rounds.	57 (89)	6 (9)	1 (2)	0 (0)	0 (0)
It was helpful to hear the entire presentation and discussion of my child during rounds.	54 (86)	7 (11)	2 (3)	0 (0)	0 (0)
The discussion during rounds was more confusing than helpful.	1 (2)	4 (6)	7 (11)	18 (28)	34 (53)
Introductions at rounds helped me identify the members of the health-care team.	28 (44)	17 (27)	12 (19)	4 (6)	2 (3)
Being present during rounds gave me more confidence in the health-care team.	42 (66)	14 (22)	7 (11)	1 (2)	0 (0)
If there is bad news, I would prefer that I be told after, not during, rounds.	16 (25)	8 (12)	12 (19)	9 (14)	19 (30)
I would prefer for the plan of care to be explained to me by one individual after rounds.	15 (23)	10 (16)	20 (31)	9 (14)	10 (16)
I felt comfortable asking questions during rounds.	35 (55)	18 (28)	5 (8)	4 (6)	2 (3)
My being present for rounds improved the care of my child.	18 (28)	10 (16)	26 (41)	5 (8)	5 (8)
If I had not been present for rounds I would have missed important information.	26 (41)	17 (27)	9 (14)	6 (9)	6 (9)
I arranged my day so that I could be present for rounds.	18 (29)	12 (19)	20 (32)	4 (6)	8 (13)
I found it upsetting when there was uncertainty expressed about the care or condition of my child during rounds.	6 (9)	16 (25)	22 (34)	8 (12)	12 (19)
I felt ignored during rounds.	3 (5)	4 (6)	8 (12)	15 (23)	34 (53)
I felt there were too many people present on rounds.	1 (2)	10 (16)	16 (25)	8 (12)	29 (45)
I had adequate time to ask questions during rounds.	27 (42)	19 (30)	8 (12)	8 (12)	2 (3)
Too many medical terms were used during rounds.	5 (8)	6 (9)	12 (19)	19 (30)	22 (34)
Attending rounds helped me to be less worried about my child.	32 (50)	22 (34)	6 (9)	3 (5)	1 (2)

Note: Sixty-one parents responded to all statements.

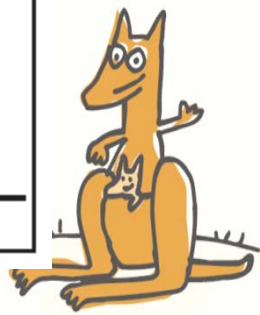


Table 4. Comparison of medical trainees' ($n = 67$) and nurses' ($n = 28$) views regarding parental presence at bedside rounds

Statement	n (%)					
	Strongly agree	*Somewhat agree*	*Neutral*	*Somewhat disagree*	*Strongly disagree*	P-value[a]
I prefer parents to be present on rounds						
Medical trainees	7 (10)	19 (28)	26 (39)	15 (22)	0 (0)	0.02
Nurses	3 (11)	15 (54)	6 (21)	4 (14)	0 (0)	
Communication with parents is improved when they are present on rounds						
Medical trainees	14 (22)	33 (51)				0.19
Nurses	5 (19)	18 (67)				
Patient care is improved when parents are present on rounds						
Medical trainees	7 (10)	21 (31)				0.93
Nurses	1 (4)	10 (37)				
I spend less time explaining patients' status and plan of care outside of roun						
Medical trainees	6 (9)	22 (33)				0.02
Nurses	4 (14)	15 (54)				
Rounds take longer when parents are present						
Medical Trainees	3 (4)	36 (54)				0.12
Nurses	11 (39)	10 (36)				
I think it is a problem that rounds take longer because parents are present[b]						
Medical Trainees	0 (0)	6 (16)				0.19
Nurses	3 (14)	4 (19)				
I think discussion among staff about a patient's condition is inhibited when parents attend rounds.						
Medical Trainees	9 (13)	40 (60)	10 (15)	6 (9)	2 (3)	0.71
Nurses	9 (35)	11 (42)	3 (12)	3 (12)	0 (0)	

Note: Sixty-three medical trainees and 25 nurses responded to all statements.
[a]Based on dichotomizing responses as Agree or Neutral/Disagree and using Pearson's χ^2 or Fisher's Exact test.
[b]Asked only to those who responded 'Strongly agree' or 'Agree' to rounds take longer when parents are present.

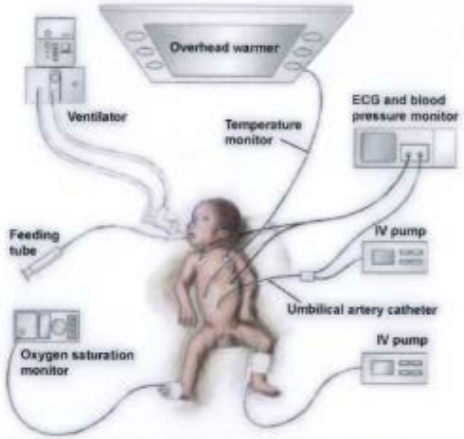
-**Residentes**: prefieren que los padres no estén-… menos educación, sensación de sentirse evaluados…
-**Enfermería** prefiere que estén
-Los dos refieren como inconveniente que **pase es más largo**…

Sant Joan de Déu

“Shared decision making” … Moore

EARLY INTENSIVE CARE

This is a photo of an extremely premature baby born at 24 weeks and receiving early intensive care.



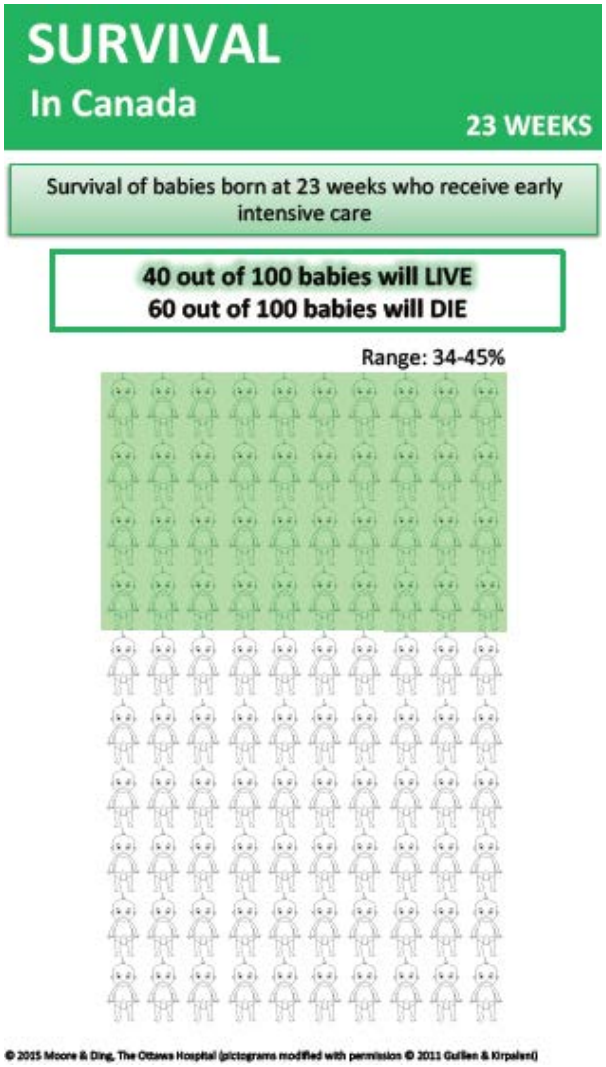
EARLY INTENSIVE CARE

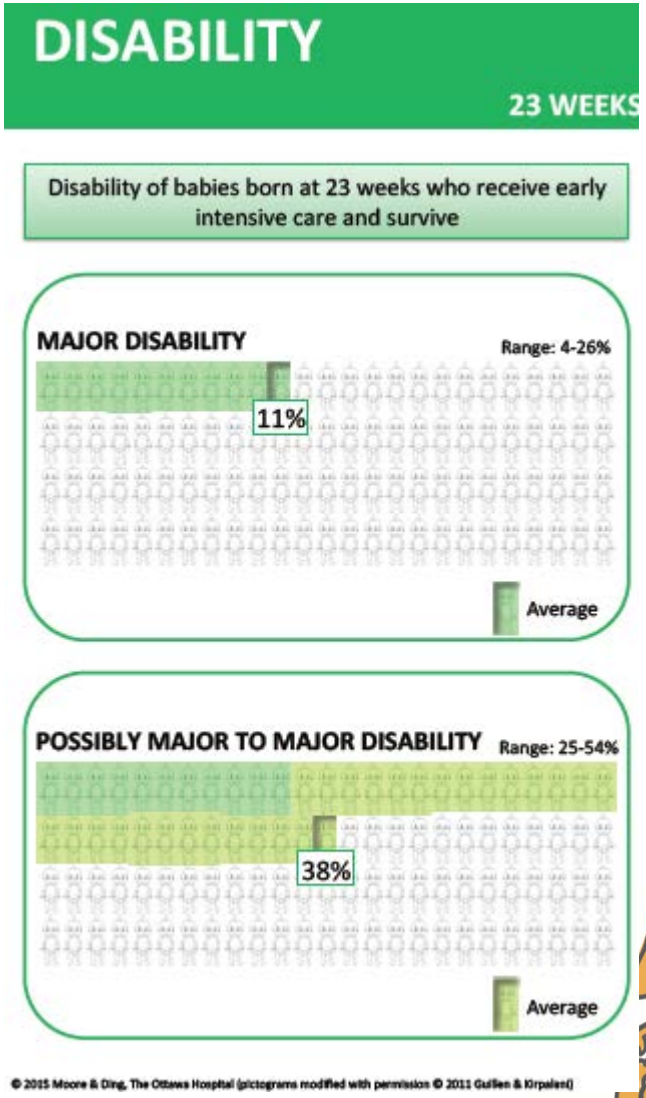
Extremely premature babies are only a little longer than the palm of your hand.

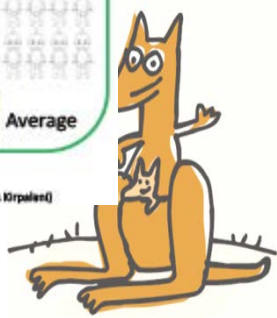
- **Resuscitation:** YES
  Will include one or more of: bag and mask ventilation, continuous positive airway pressure (CPAP), intubation, mechanical ventilation, intravenous access, chest compressions and epinephrine
- **Painful procedures:** YES
- **Duration of care for the baby:** Months in the NICU (neonatal intensive care unit).
- **Support Available:** YES

PALLIATIVE CARE

Palliative care gives you time to hold your baby, who will be wrapped in blankets and given comfort.

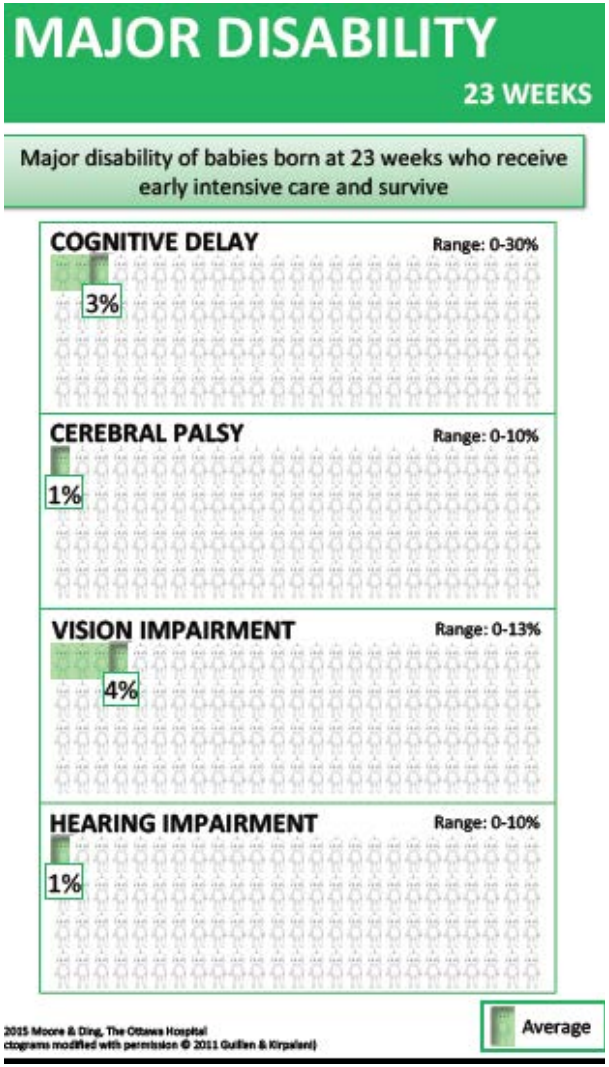






Moore et al

www.sdmforepi.com



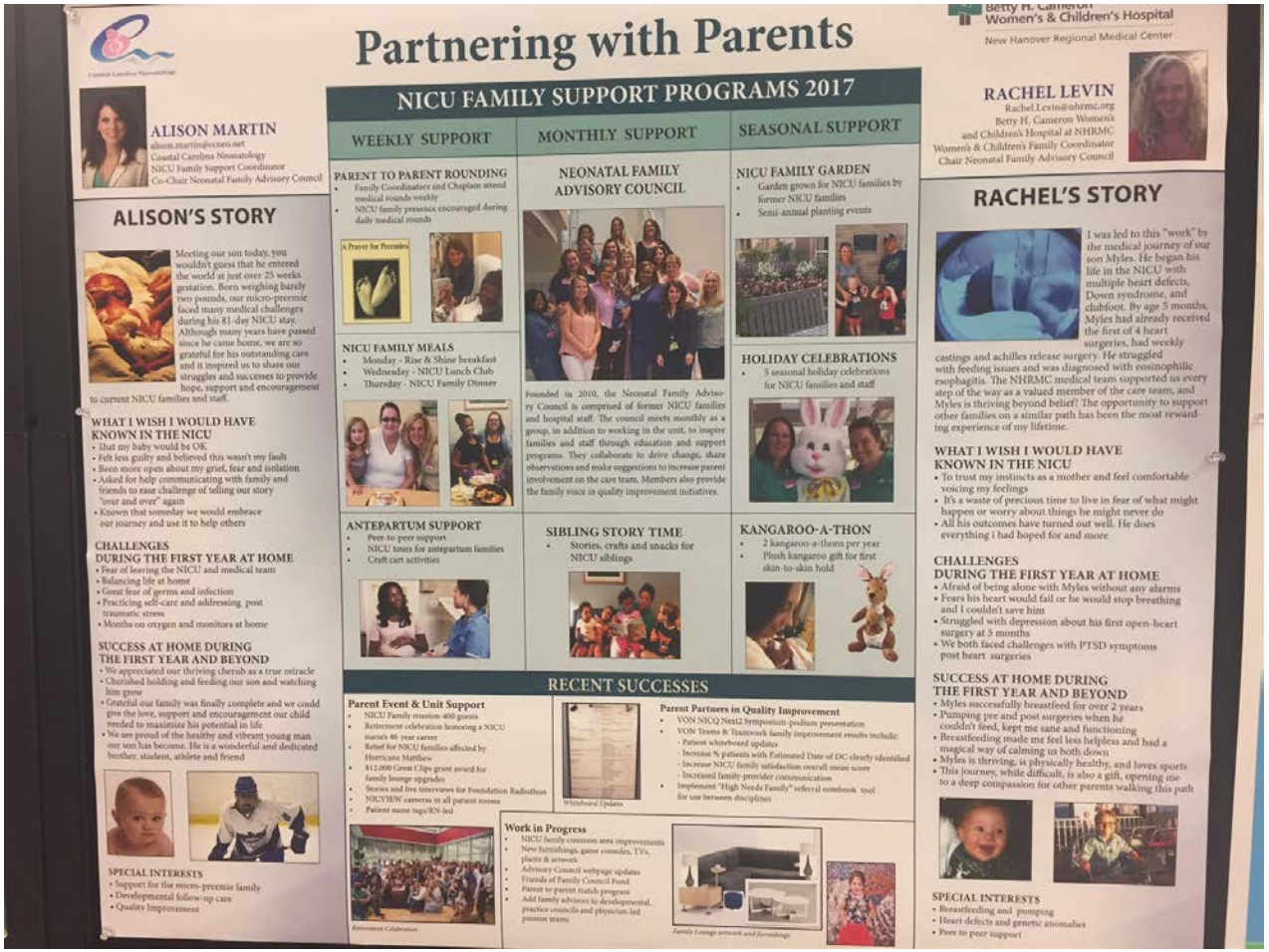
	Most common	Less common	Least common		
Disability	**Cognitive Function**	**Movement or Motor**	**Hearing**	**Vision**
Mild	Learning difficulties	Clumsy, difficulties with paper and pencil	Mild hearing loss	Needs glasses
Possibly Major	Slower than average; learns with support	Cerebral palsy; expected to walk with help	Hearing loss; corrected with hearing aids	Poor eyesight, even with glasses
Major	Very slow, needs lifelong care	Cerebral palsy; cannot walk without help or cannot walk	Deaf; cannot hear even with hearing aids	Blind

The graphs on the following page illustrate the estimated risk of major and possibly major disability for babies born at 22 to 25 weeks of gestation who are alive at school age (4-8 years old). Note that the darkened bar refers to the babies born at 24 weeks.

Moore et al

www.sdmforepi.com

Familias integradas en la unidad



VON Annual Congress Chicago 2017

Cómo conclusión…

Sant Joan de Déu

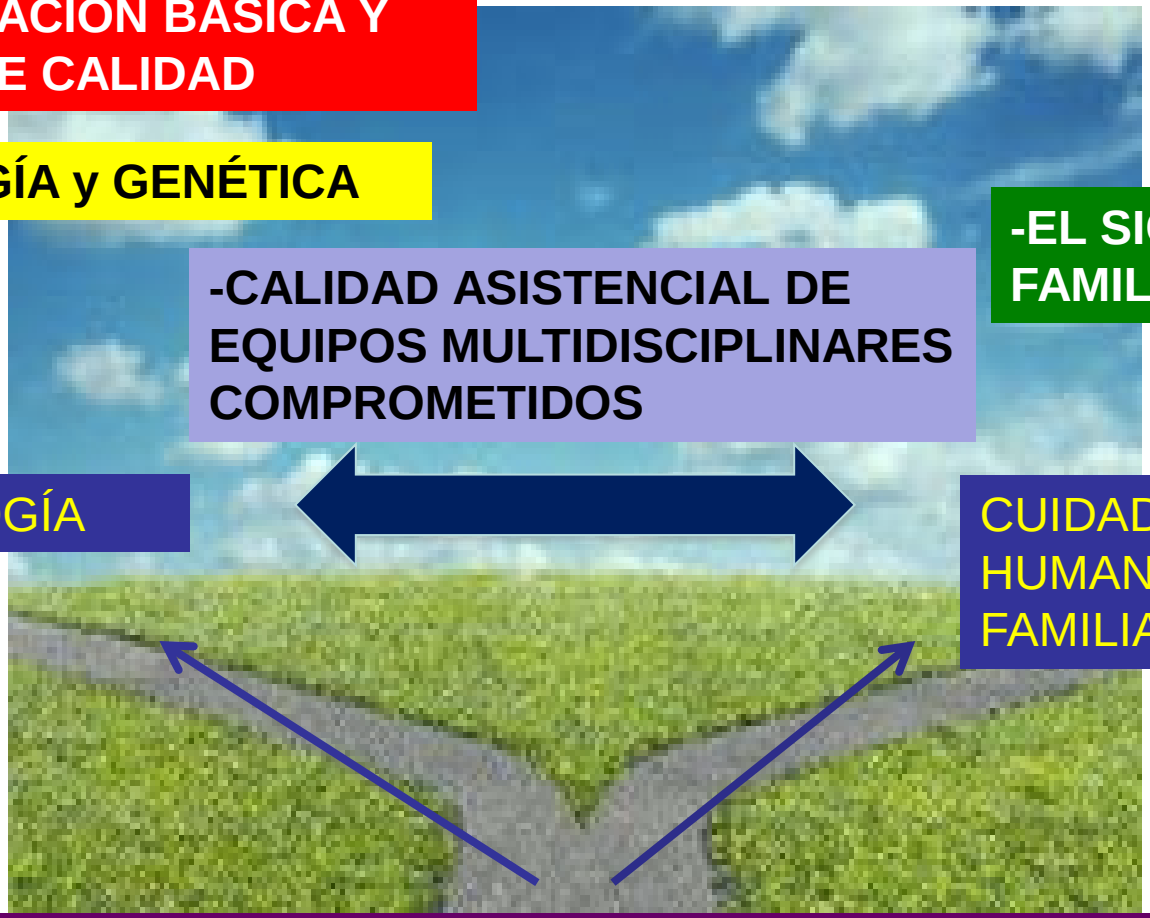
Conclusiones: en el siglo XXI…

-INVESTIGACIÓN BÁSICA Y CLÍNICA DE CALIDAD

-TECNOLOGÍA y GENÉTICA

-EL SIGLO DE LAS FAMILIAS

-CALIDAD ASISTENCIAL DE EQUIPOS MULTIDISCIPLINARES COMPROMETIDOS



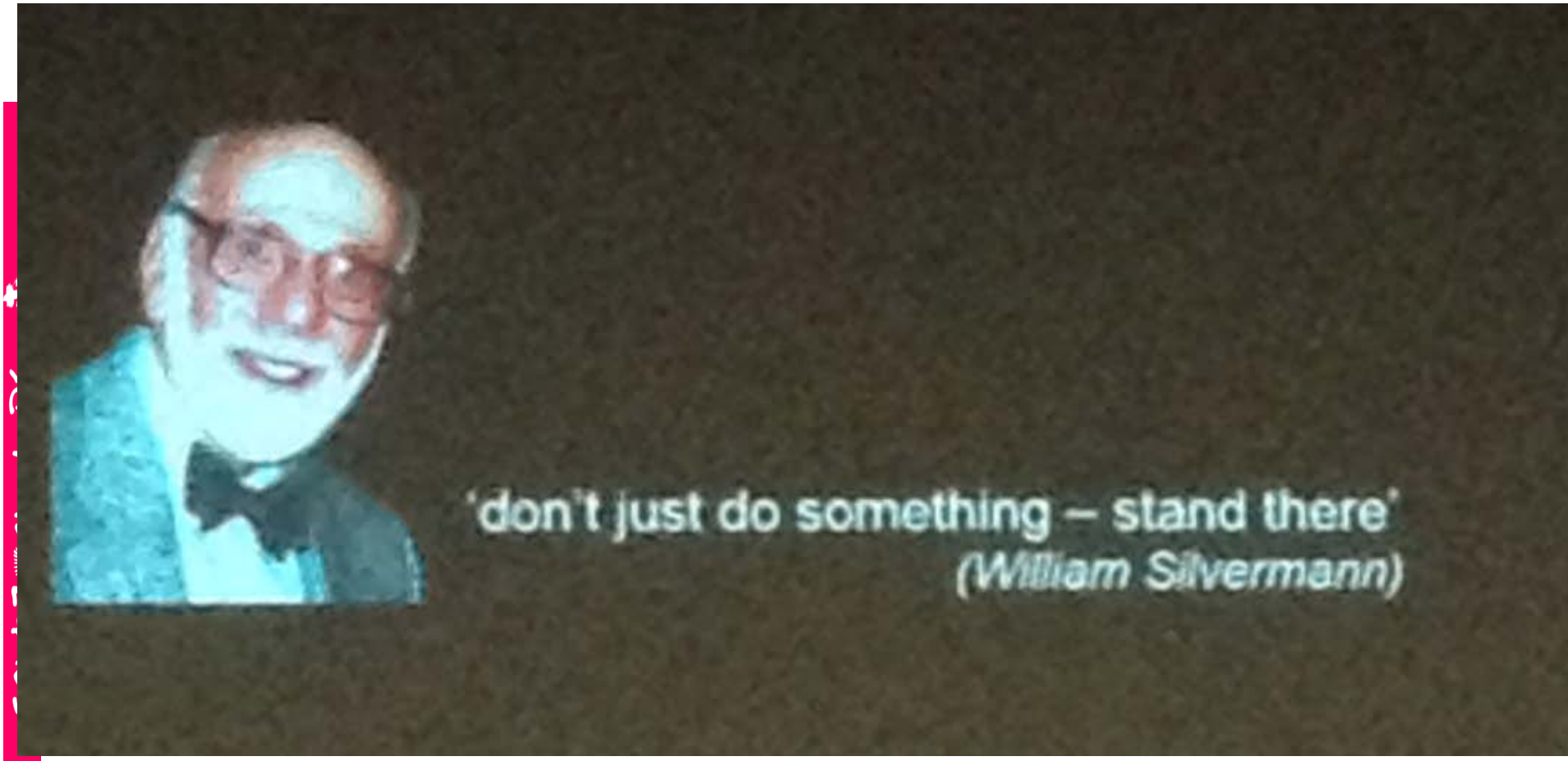
TECNOLOGÍA

CUIDADOS MÁS HUMANIZADOS + FAMILIAS

-RESOVER RETOS ANTIGUOS Y LOS QUE PUEDAN APARECER

En tiempos de inmediatez…

-No olvidar el peligro de “querer ir demasiado rápido…”



GRACIAS

World Prematurity Day 17 November

1 baby in 10 is born premature. Worldwide.