



**L'assistenza ai GUCH: ruolo del cardiologo, passaggio di testimone fra Pediatra e Medico di Medicina Generale.**

Giorgio Faganello

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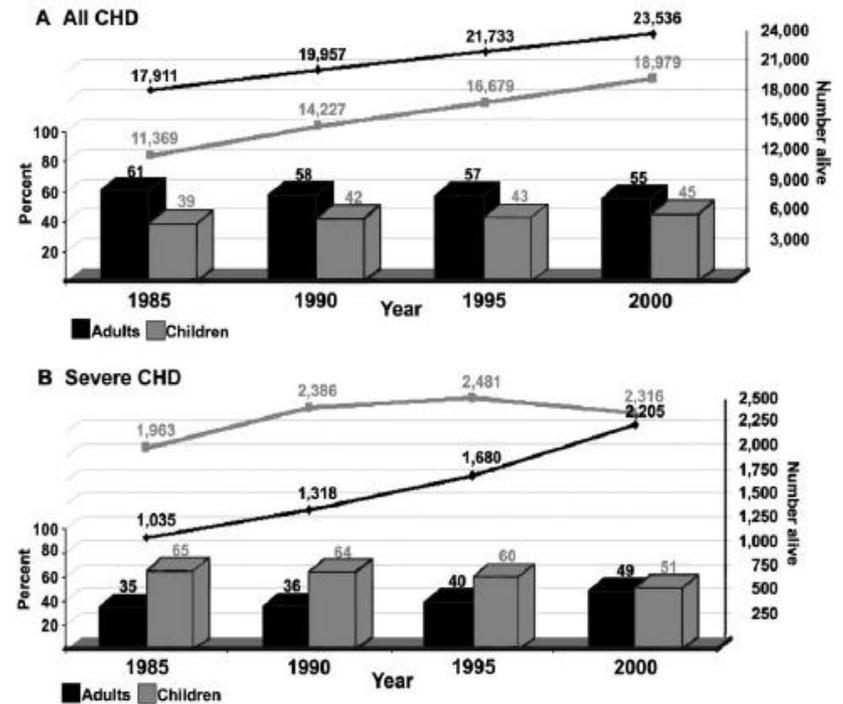
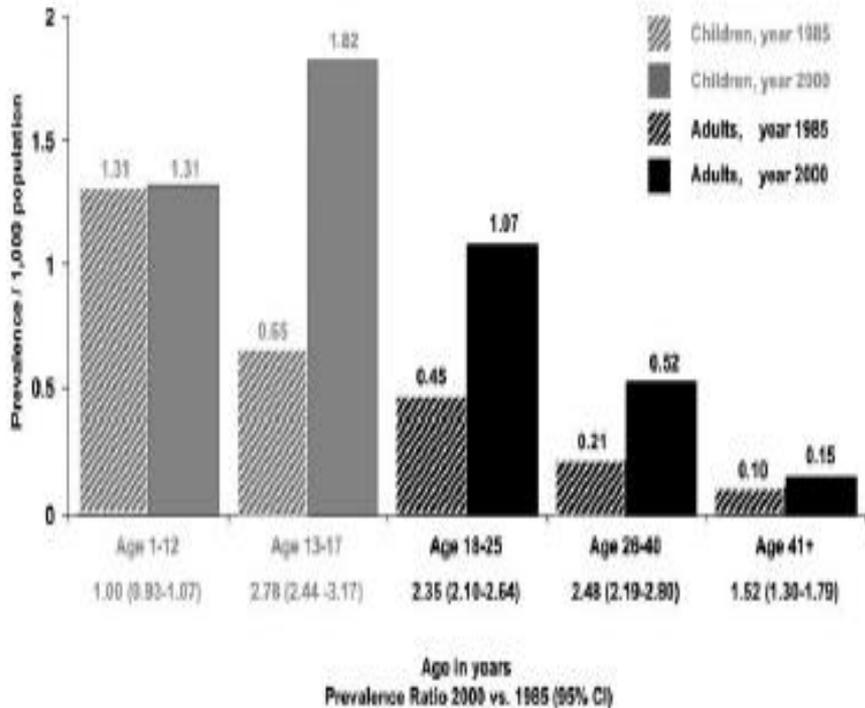


## L'assistenza ai GUCH: ruolo del cardiologo, passaggio di testimone fra Pediatra e Medico di Medicina Generale.



### Congenital Heart Disease in the General Population Changing Prevalence and Age Distribution

Ariane J. Marelli, MD; Andrew S. Mackie, MD, SM; Raluca Ionescu-Ittu, MSc;  
Elham Rahme, PhD; Louise Pilote, MD, MPH, PhD



**IL PASSAGGIO TRA L'ADOLESCENZA E L'ETA' ADULTA VIENE DETTO**

**PROCESSO DI TRANSIZIONE**

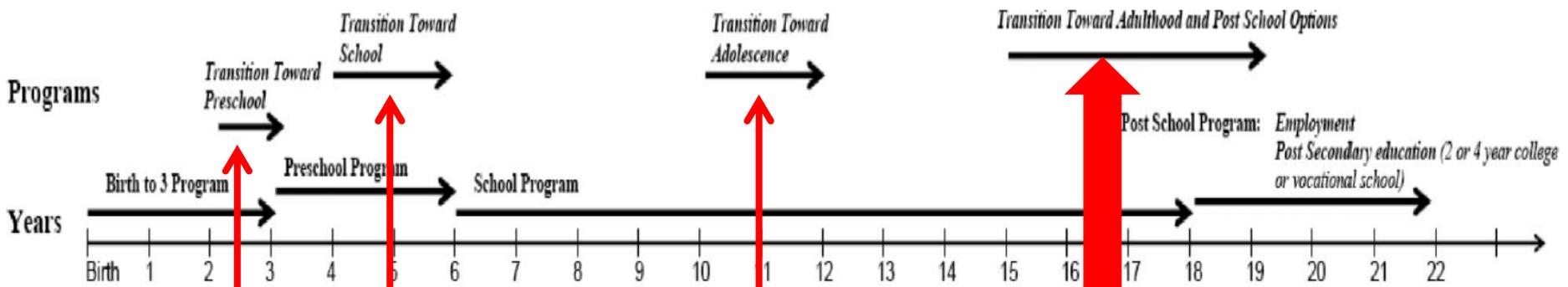
- “Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult orientated health care systems.”

*(Blum et al, 1993).*

## Quando inizia il processo della transizione?

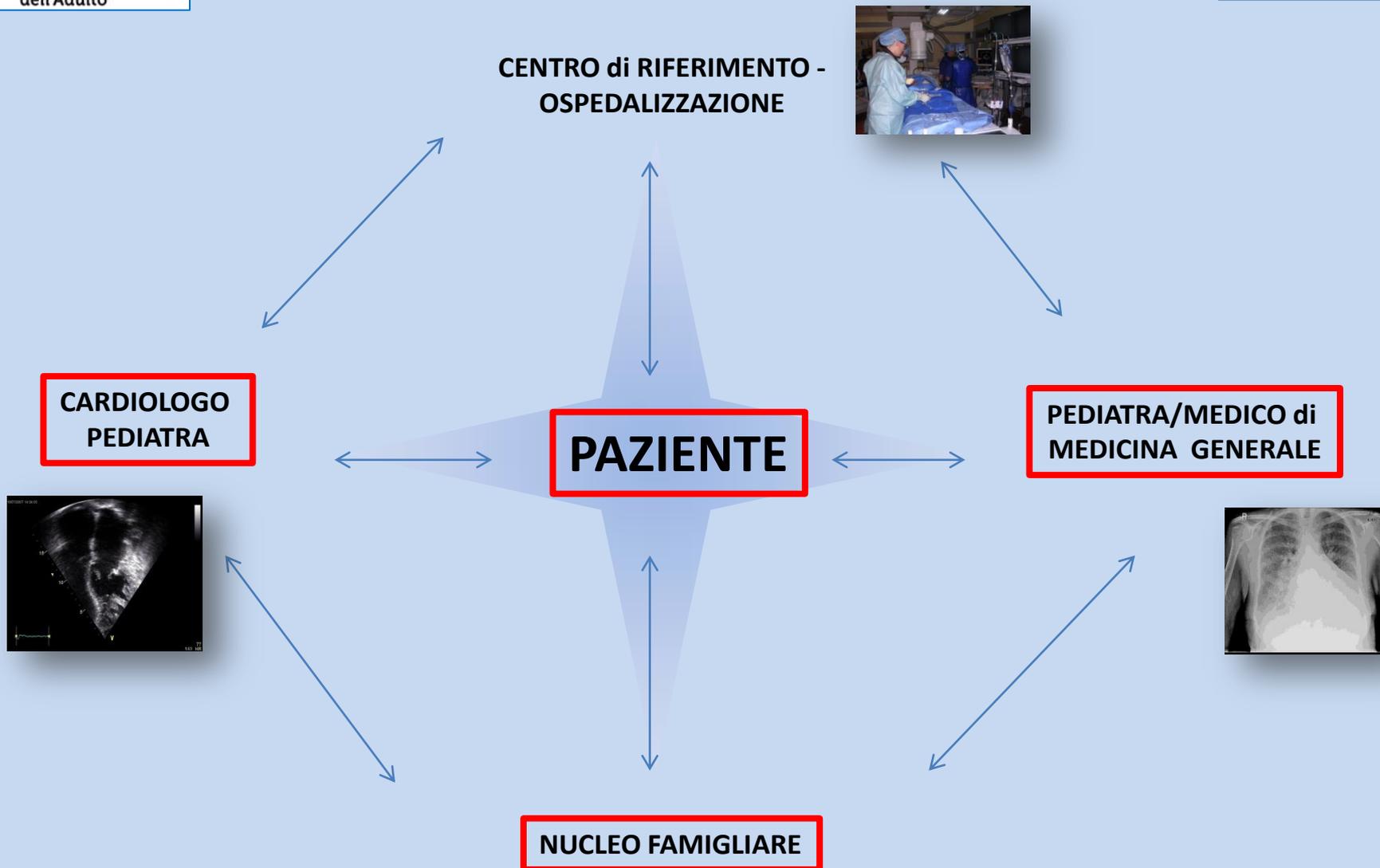


**Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues**  
**A Scientific Statement From the American Heart Association**  
*(Circulation. 2011;123:1454-1485)*



SSI indicates Supplemental Security Income.

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**NEL PASSAGGIO ALL'ETA' ADULTA...**



Ambulatorio  
Cardiopatie Congenite  
dell'Adulto

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CARDIOLOGO  
PEDIATRA

CENTRO di RIFERIMENTO/  
OSPEDALIZZAZIONE



MEDICO di MEDICINA  
GENERALE

PAZIENTE



MONDO REALE

CARDIOLOGO ADULTO  
GUCH



Ambulatorio  
Cardiopatie Congenite  
dell'Adulto

## **Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues**

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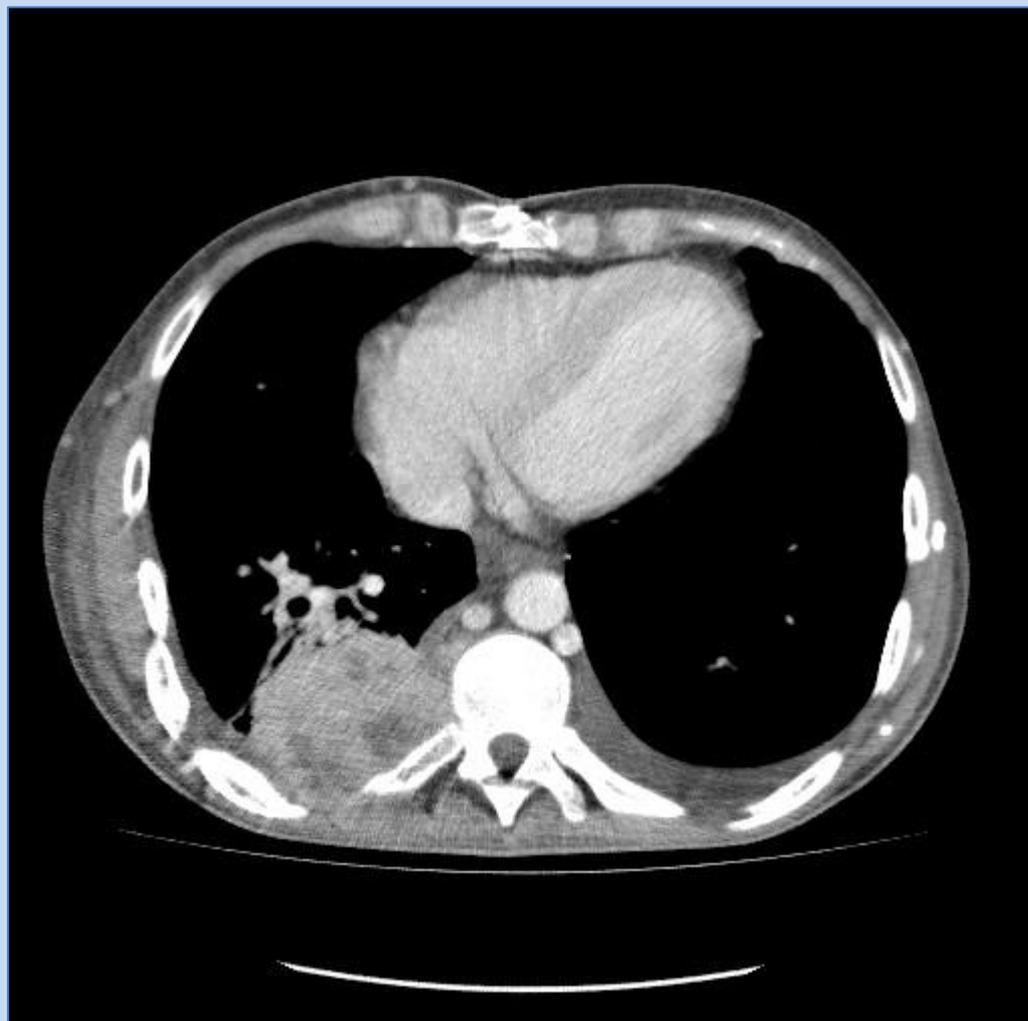
health care as they leave their pediatric providers. The American Academy of Pediatrics' Medical Home Initiative states that 90% of children with special needs reach their 21st birthday, yet 45% of them lack access to a physician who is familiar with their condition(s). In addition, 30% of all young adults 18 to 24 years of age lack a payment source for their health care.<sup>18</sup> The Maternal Child Health Bureau, a division

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**Quanto automatico è il passaggio  
del testimone?**

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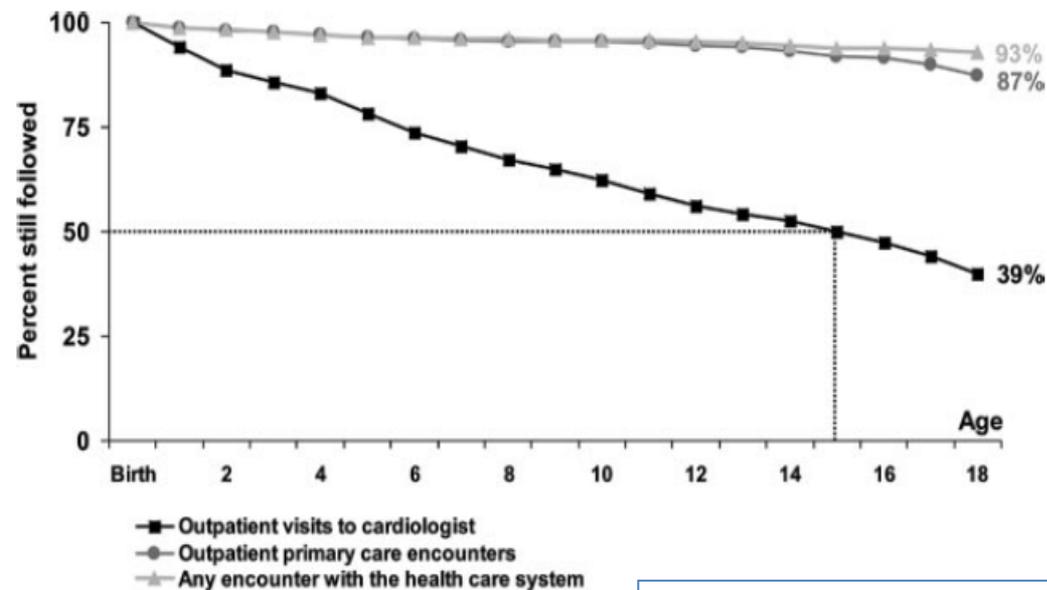
## Children and Adults With Congenital Heart Disease Lost to Follow-Up Who and When?

Andrew S. Mackie, MD, SM; Raluca Ionescu-Ittu, MSc; Judith Therrien, MD;  
Louise Pilote, MD, MPH, PhD; Michal Abrahamowicz, PhD; Ariane J. Marelli, MD

Dal 1983. Pts >6yrs.

F-up al 6° - 13° e 18° anno di età.

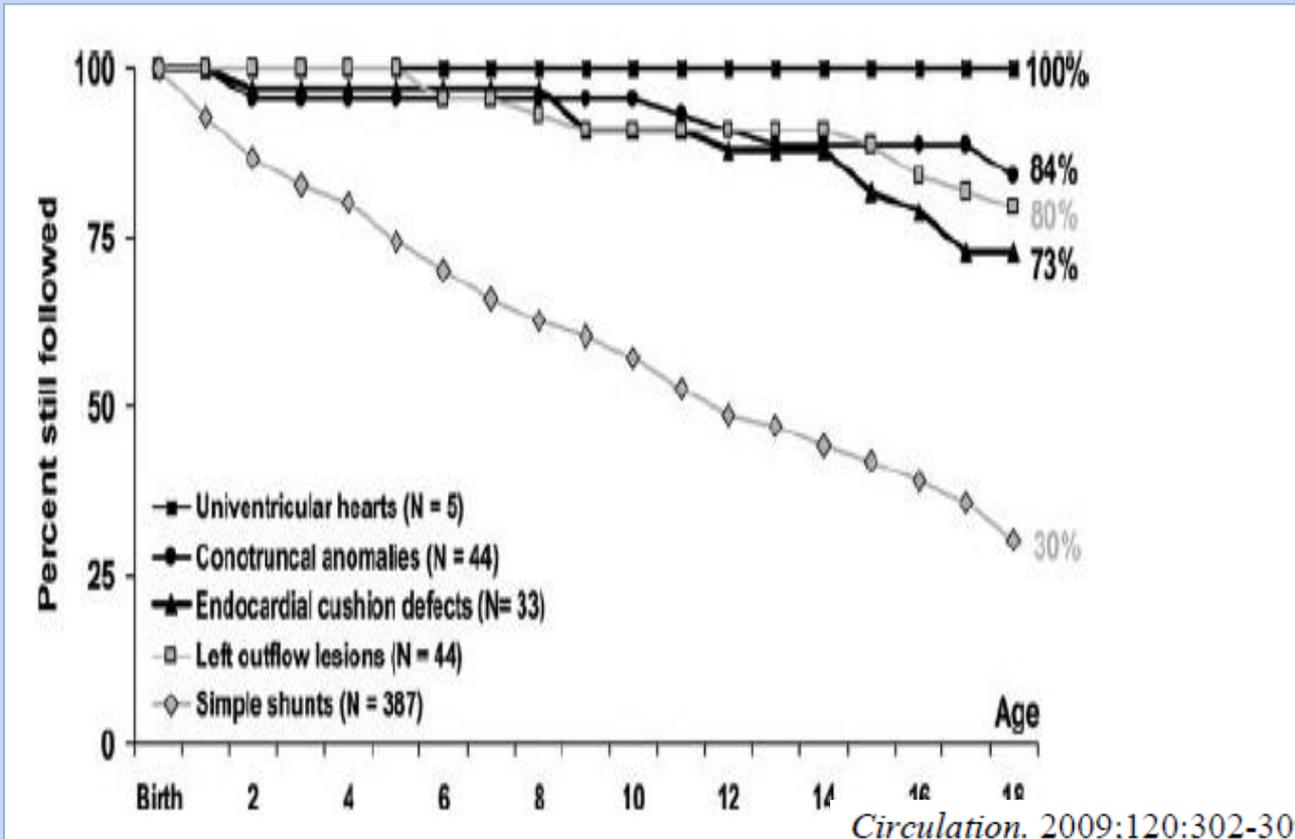
Lost fup in 28% - 47% - 61% respectively.



*Circulation. 2009;120:302-309*

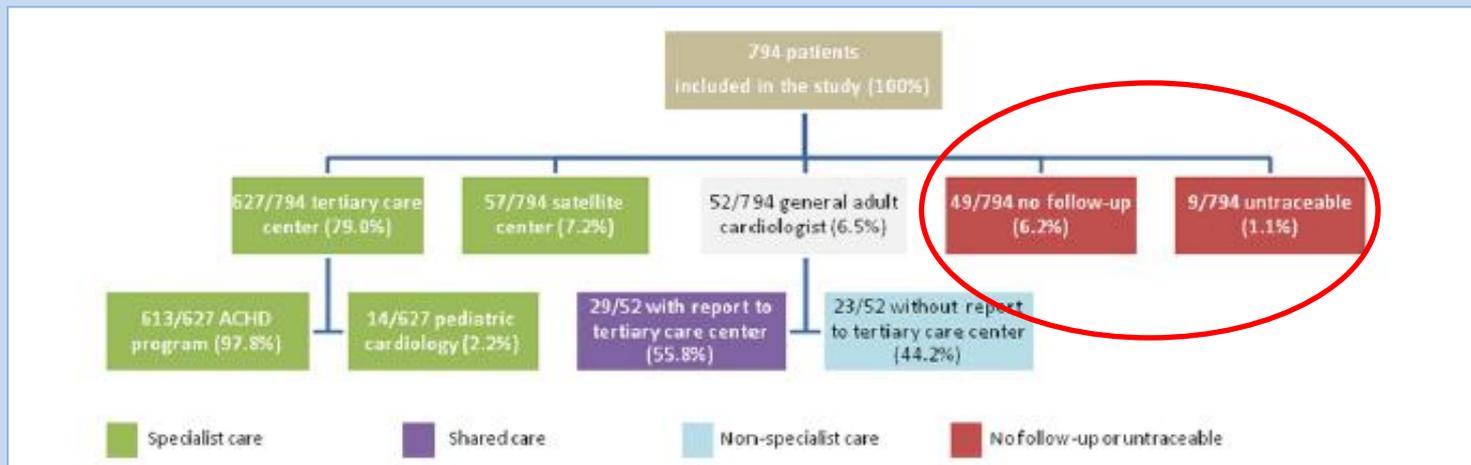
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### Congenital Heart Disease

# Transfer of Adolescents With Congenital Heart Disease From Pediatric Cardiology to Adult Health Care





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# Perché viene perso il follow up?

## Risk factors for loss to follow-up among children and young adults with congenital heart disease

Andrew S. Mackie,<sup>1</sup> Gwen R. Rempel,<sup>2</sup> Kathryn N. Rankin,<sup>1</sup> David Nicholas,<sup>3</sup> Joyce Magill-Evans<sup>4</sup>

74 ACHD pts.

Età media 13 aa.

controls had methods to remember appointments. *Conclusions:* A history of one or more missed cardiology appointments predicted loss to follow-up for 3 or more years, as did lack of awareness of the need for follow-up. Higher family income, recent catheterisations, and medical record documentation of the need for follow-up were protective.

*Cardiology in the Young* (2012), 22, 307-315

## Prevalence and Correlates of Successful Transfer From Pediatric to Adult Health Care Among a Cohort of Young Adults With Complex Congenital Heart Defects

Graham J. Reid, PhD\*†§¶; M. Jane Irvine, PhD‡||#; Brian W. McCrindle, MD\*\*††; Renee Sananes, PhD‡ ††;  
Paul G. Ritvo, PhD‡||†† §§; Samuel C. Siu, MD§||¶; and Gary D. Webb, MD§||¶

PEDIATRICS Vol. 113 No. 3 March 2004

360 pts



234 pts

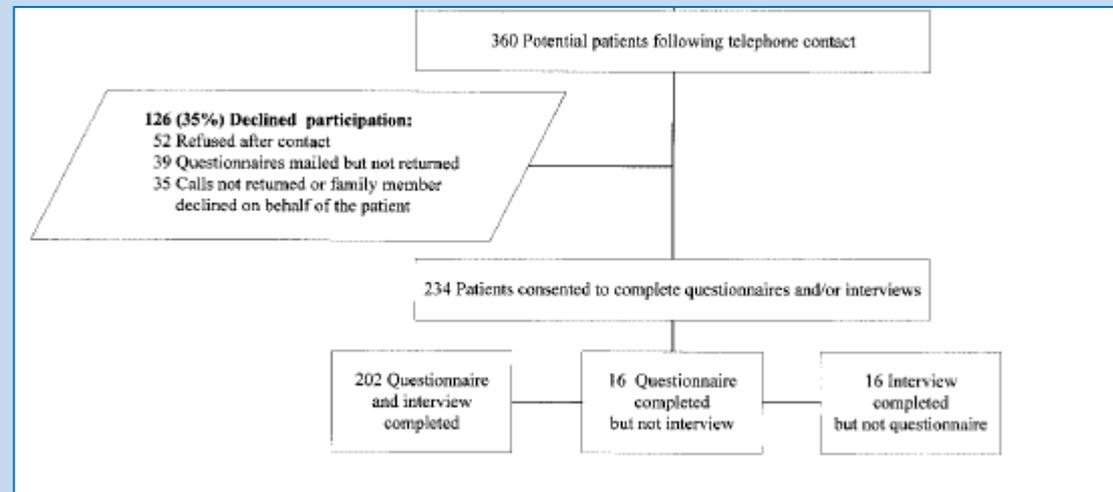
Età 19-21 aa

ACHD complessi



47% ha completato

Il transfer con successo



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Paul G. Ritvo, PhD‡||†† §§; Samuel C. Siu, MD§||¶; and Gary D. Webb, MD§||¶

PEDIATRICS Vol. 113 No. 3 March 2004

In multivariate analyses of the entire cohort, successful transfer was significantly associated with more pediatric cardiovascular surgeries (odds ratio [OR]: 2.47; 95% CI: 1.40–4.37), older age at last visit to the Hospital for Sick Children (OR: 1.29; 95% CI: 1.10–1.51), and documented recommendations in the medical chart for follow-up at a CACH center. In multivariate analyses of the patients completing questionnaires, successful transfer was significantly related to documented recommendations and patient beliefs that adult CHD care should be at a CACH center (OR: 3.64; 95% CI: 1.34–9.90). Comorbid conditions (OR: 3.13; 95% CI: 1.13–8.67), not using substances (eg, binge drinking; OR: 0.18; 95% CI: 0.07–0.50), using dental antibiotic prophylaxis (OR: 4.23; 95% CI: 1.48–12.06), and attending cardiac appointments without parents or siblings (OR: 6.59; 95% CI: 1.61–27.00) also correlated with successful transfer.

**Congenital Heart Disease**

**Transfer of Adolescents With Congenital Heart Disease  
From Pediatric Cardiology to Adult Health Care**

**Quali sono i problemi derivanti dalla  
perdita del follow up?**

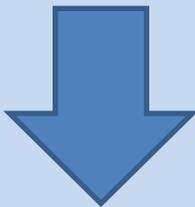
## Congenital Heart Disease

# Trends in Hospitalizations for Adults With Congenital Heart Disease in the U.S.

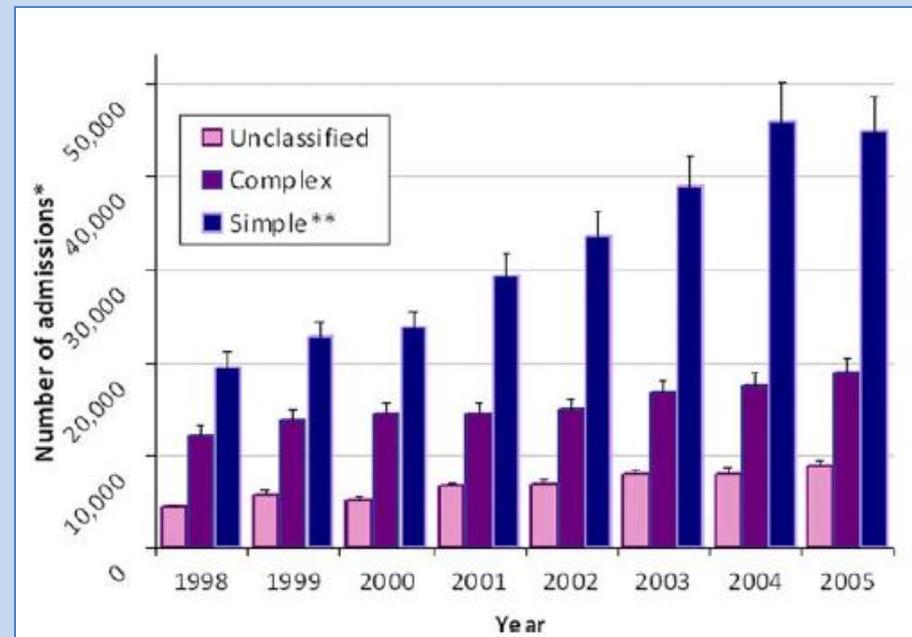
(J Am Coll Cardiol 2009;54 460-7)

Età  $53 \pm 0.6$  yrs

**1998**     $35992 \pm 2645$



**2005**     $72656 \pm 5258$



**Congenital Heart Disease**

**Trends in Hospitalizations for Adults  
With Congenital Heart Disease in the U.S.**

(J Am Coll Cardiol 2009;54 460-7)

**Table 3** Frequency of Specific Diagnoses and Procedures Associated With Hospitalizations for ACHD

Year	1998	1999	2000	2001	2002	2003	2004	2005	Total
<b>Diagnoses*</b>									
Arrhythmia	11,742 (1,012)	12,717 (1,047)	13,218 (994)	16,332 (1,261)	17,713 (1,352)	20,174 (1,597)	22,458 (1,896)	24,882 (1,961)	139,237 (5,303)
CAD†	8,574 (745)	9,395 (727)	10,770 (853)	12,843 (1,037)	14,275 (1,105)	16,191 (1,279)	18,440 (1,549)	18,788 (1,455)	109,275 (4,235)
Heart failure	7,453 (624)	8,168 (588)	8,389 (584)	9,628 (649)	10,427 (793)	12,1 (908)	12,939 (1,064)	13,604 (1,008)	83,130 (2,905)
Pulmonary hypertension	3,923 (294)	4,747 (402)	4,774 (372)	4,989 (383)	5,617 (446)	6,284 (506)	6,652 (652)	6,528 (525)	43,516 (1,702)
Pregnancy	1,706 (162)	2,217 (204)	2,149 (202)	2,036 (179)	2,568 (226)	2,669 (235)	2,990 (270)	3,431 (312)	19,765 (822)
Bacterial endocarditis	574 (71)	648 (80)	578 (69)	765 (79)	802 (89)	802 (90)	1,103 (116)	867 (99)	6,138 (296)
<b>Procedures</b>									
Percutaneous ASD/PFO closure	134 (90)	165 (59)	308 (133)	627 (150)	2,205 (662)	3,517 (1,008)	4,415 (1,043)	3,219 (566)	14,589 (2,413)
Pacemaker	974 (150)	1,332 (145)	1,310 (148)	1,427 (52)	1,638 (198)	1,798 (191)	2,021 (208)	2,188 (235)	12,687 (674)
PCI	830 (103)	806 (103)	1,065 (136)	1,130 (130)	1,405 (155)	1,832 (198)	1,967 (247)	2,227 (239)	11,262 (633)
ICD	208 (45)	368 (69)	326 (52)	602 (85)	570 (81)	662 (88)	901 (130)	840 (109)	4,476 (312)

## Loss to specialist follow-up in congenital heart disease; out of sight, out of mind

Jo Wray, Alessandra Frigiola, Catherine Bull, Adult Congenital Heart disease Research Network (ACoRN)

Wray J, et al. *Heart* 2013;**99**:485–490.

**1085 Fallot repairs**

100 deaths first p.o. year  
 17 known to have moved abroad  
 27 untracked (no NHS number ascertained)  
 48 deaths after first p.o. year

**893 alive and in UK with current names, NHS numbers and GP addresses**

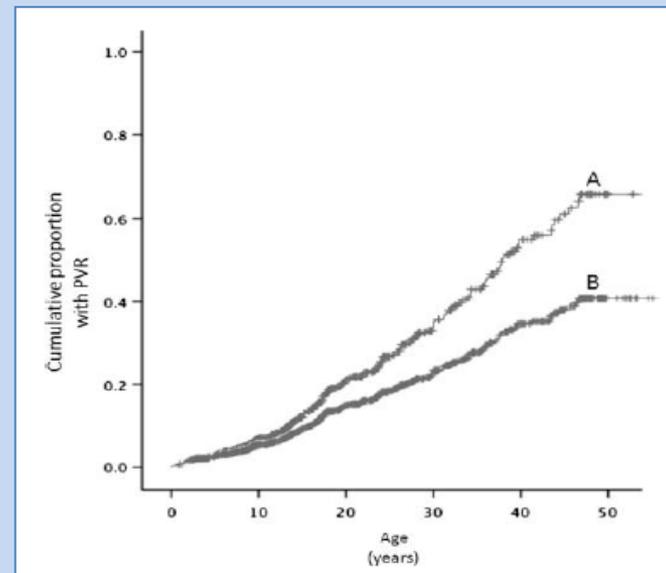
677 actively followed in specialist clinics

**216 not seen for >3 years in any specialist clinic ( 194 adults, 22 children)**

176 GP letters sent (106 replies received, including 6 'don't contact')

100 letters to patients (all adults)  
 42 patients agreed to be contacted

**37 successfully contacted by telephone**



24% non sono seguiti da ACHD specialist da almeno 3 aa  
 48% dei decessi tardivi sono in pazienti "lost in f-up"

Proporzione cumulativa per età di PVR  
 A. pts in f-up.      B. tutti i TOF.

## Outcomes of Heart Failure–Related Hospitalization in Adults with Congenital Heart Disease in the United States

Fred H. Rodriguez III, MD,\*<sup>¶</sup> Douglas S. Moodie, MD,\* Dhaval R. Parekh, MD,\*  
Wayne J. Franklin, MD,\* David L.S. Morales, MD,<sup>†</sup> Farhan Zafar, MD,\*  
Gerald J. Adams, EdD, PStat,\* Richard A. Friedman, MD,<sup>‡</sup> and Joseph W. Rossano, MD<sup>§</sup>

20% delle ospedalizzazioni per ACHD pts ha diagnosi di scompenso cardiaco  
Età media 63.9 aa

**Table 1.** Baseline Characteristics during Hospitalization of Adults with Congenital Heart Disease

Demographics	Hospitalizations without Heart Failure (n, 95% CI)	Hospitalizations with Heart Failure (n, 95% CI)
ACHD admissions	67 115 (60 396–73 834)	17 193 (14 157–20 229)
Female gender	51.3% (50.1–52.5%)	52.4% (50.2–54.5%)
Age groups		
Ages 18–30	9 308 (13.9%, 12.6–15.2%)	997 (5.8%, 4.8–7.0%)
Ages 31–50	20 202 (30.1%, 29.0–31.2%)	3 210 (18.7%, 16.8–20.7%)
Ages 51–65	18 383 (27.4%, 26.5–28.4%)	3 959 (23.0%, 21.5–24.7%)
Ages >65	19 222 (28.6%, 27.2–30.1%)	9 027 (52.5%, 49.7–55.3%)
Length of stay (days), mean	5.1 (4.9–5.2)	7.6 (7.2–8.1)

**Table 7.** Mortality of Adult Congenital Heart Disease Patients during Heart Failure–Related Hospitalization by Age Groups

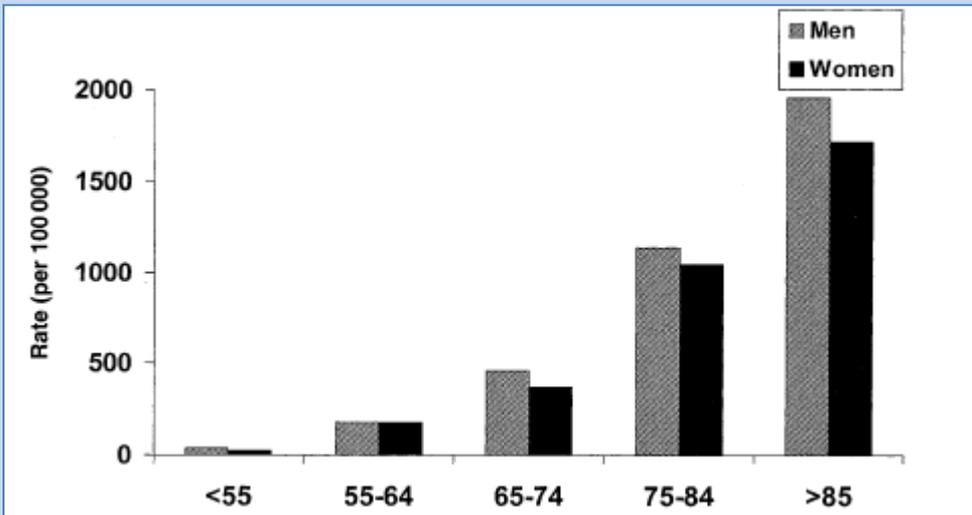
Age Groups (Years)	Mortality (% , 95% CI)
18–30	5.2 (3.0–8.8)
31–50	4.7 (3.4–6.6)
51–65	2.6 (1.7–3.9)
>65	4.4 (3.5–5.5)

*P* = .097

**Mortalità intraospedaliera in presenza di ACHD 4.1%**

# Incidence and hospital death rates associated with heart failure: A community-wide perspective

The American Journal of Medicine (2005) 118, 728-734



Pts ricoverati per HF (no ACHD)

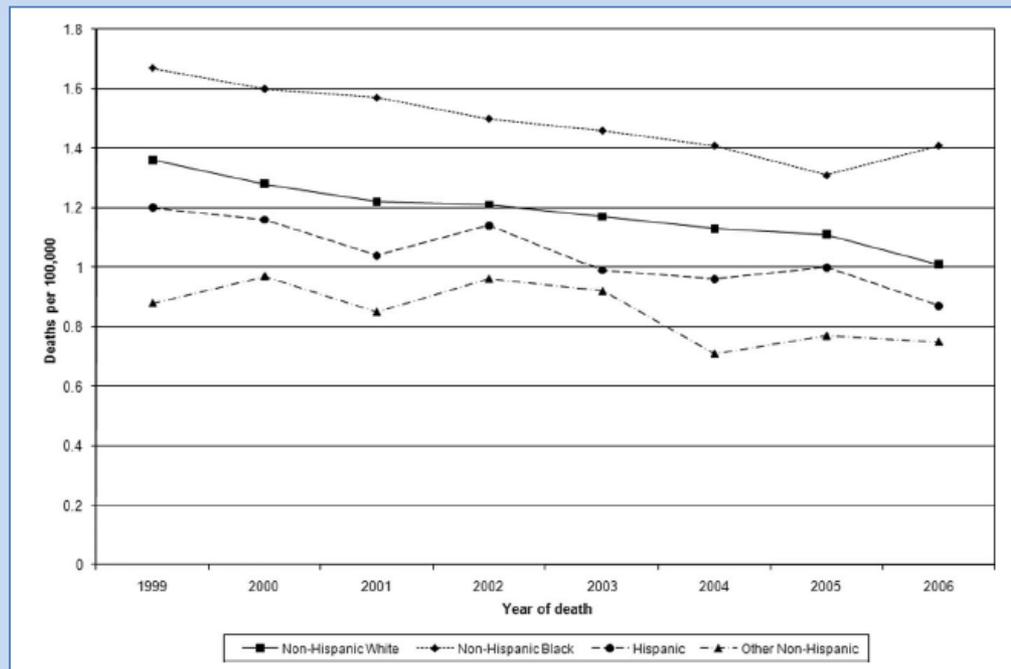
Età media 78 aa

**Mortalità intraospedaliera 5.1%**

# Mortality Resulting From Congenital Heart Disease Among Children and Adults in the United States, 1999 to 2006

Suzanne M. Gilboa, PhD; Jason L. Salemi, MPH; Wendy N. Nembhard, PhD;  
David E. Fixler, MD; Adolfo Correa, MD, PhD

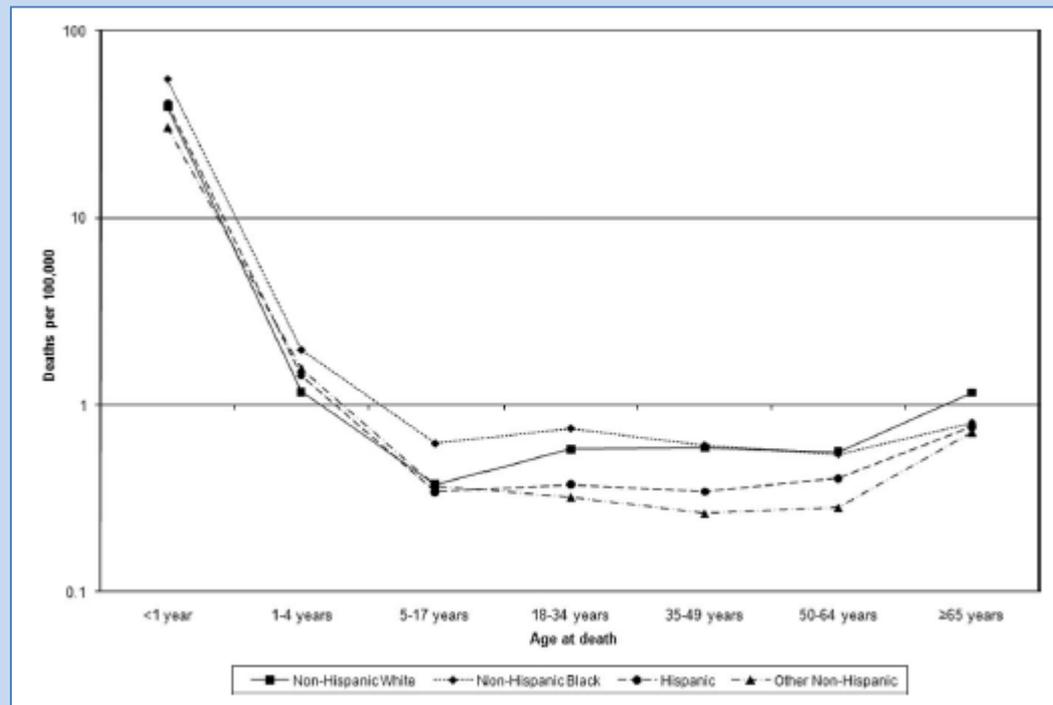
*Circulation* 2010;122:2254-2263



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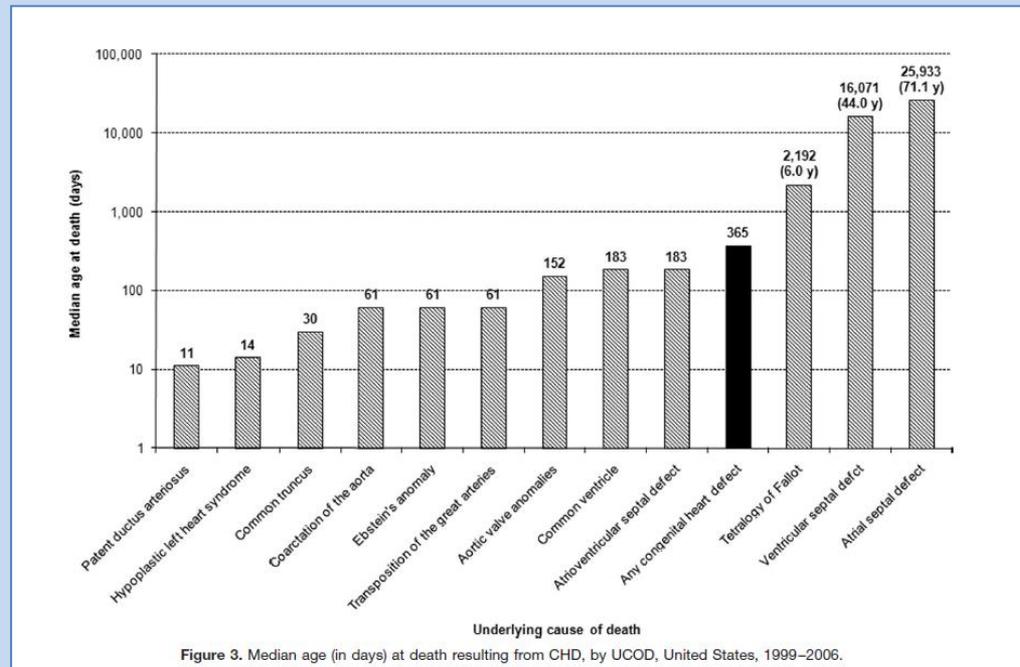


Figure 3. Median age (in days) at death resulting from CHD, by UCOD, United States, 1999–2006.

## L'assistenza ai GUCH: ruolo del cardiologo, passaggio di testimone fra Pediatra e Medico di Medicina Generale.



### Come siamo organizzati a TS

**CARDIOLOGO  
PEDIATRA**



**CARDIOLOGO ADULTO  
GUCH**



Fisicamente in due ospedali diversi della città di Trieste.

Segnalazione automatica tramite mail per presa i carico delle ACHD più semplici.

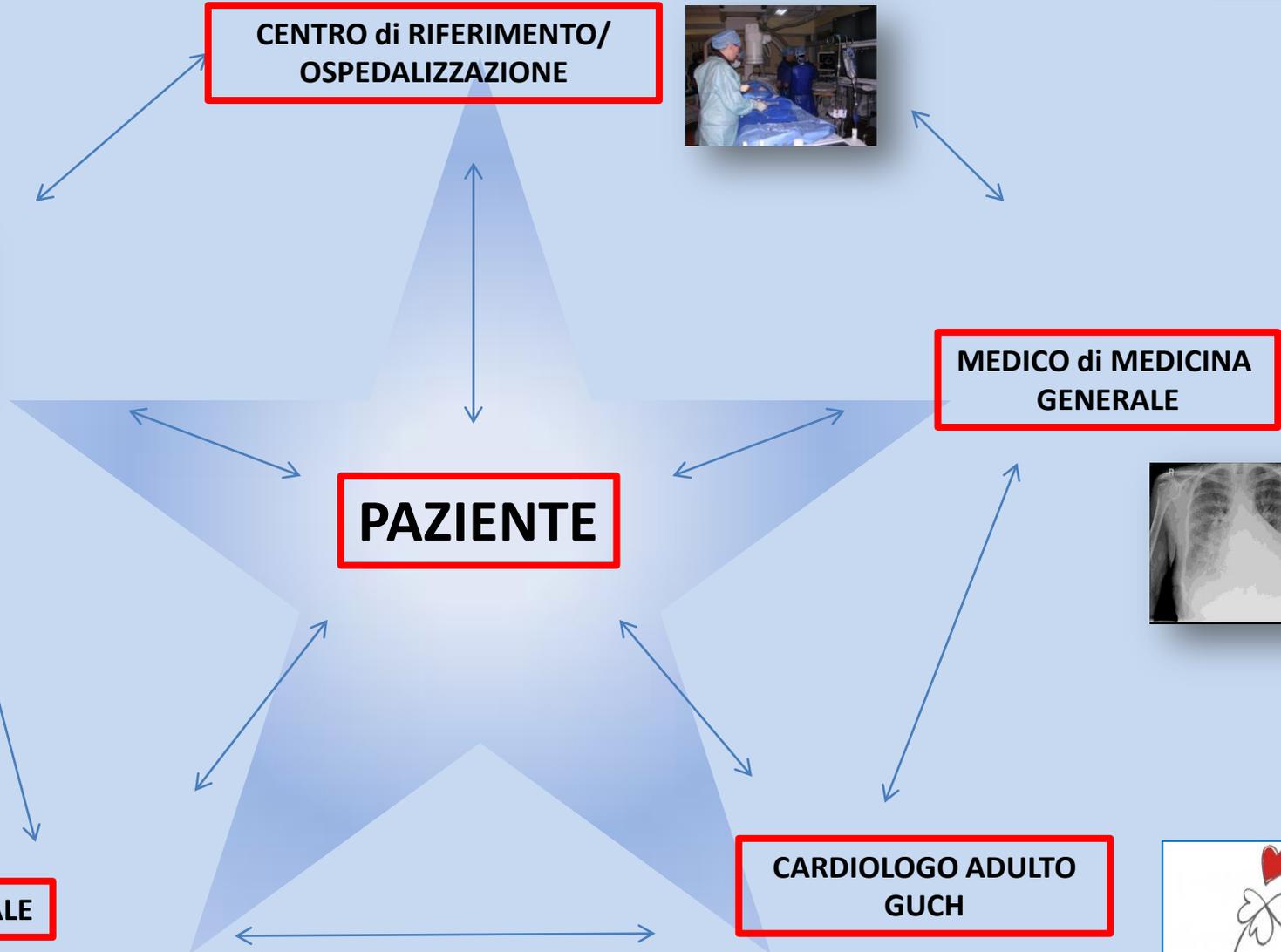
Nel 2013 aumentata la collaborazione tra le due realtà.

Una volta al mese, visita ambulatoriale in comune sptt nei pazienti in età di transizione più complessi.

Discussione collegiale dei casi clinici.

Esecuzione di esami strumentali in cardiopatie più complesse in pazienti pediatrici: 3DTEE, CPET, MRI cuore.

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**GRAZIE**