

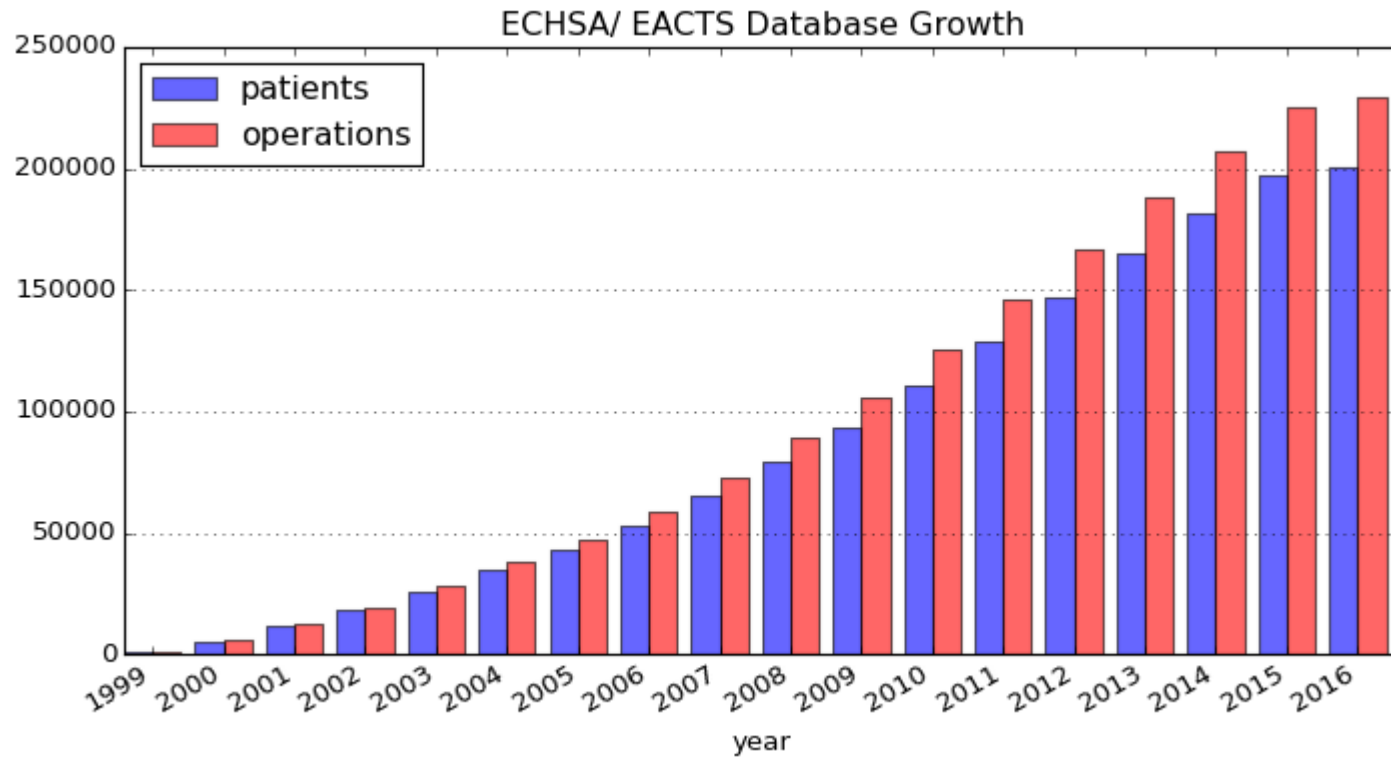


5th Scientific Meeting & Annual Members Meeting
World Society for Pediatric and Congenital Heart Surgery

Status and Challenges of Care for Adult Congenital Heart Disease in Europe

Bohdan Maruszewski, Warsaw, Poland

Abu Dhabi, UAE October 27 – 30, 2016





Patients and Operations by Continents

continent	no of patients	% of patients	no of operations	% of operations
Europe	133572	72.02	168205	73.33
Asia	34779	18.75	39117	17.05
Australia and Oceania	6836	3.69	10449	4.56
South America	6112	3.30	6944	3.03
Africa	4077	2.20	4585	2.00
North America	80	0.04	85	0.04



All patients 1999 - 2016

Results

Number of patients: 185456

Number of procedures: 229385

Number of deaths (30 day): 7570

Mortality (30 day): 4.08%

Number of deaths (hospital): 8441

Mortality (hospital): 4.55%

	No of cases	% of all	Min	Mean	Stddev	Max
IPPV (hour)	145811	63.57	1	74.50	225.60	8650
CPB time (min)	163610	71.33	1	106.66	69.79	999
Aortic X time (min)	143660	62.63	1	60.88	41.97	578
Circulatory arrest (min)	13012	5.67	1	31.39	20.59	100
Weight (kg)	226641	98.80	0.36	16.90	20.89	190
Age at operation (month)	229384	100.00	0	68.66	133.79	1275
LOS (day)	229385	100	0	14.89	21.72	515



Basic Reports - Number of Patients by Age Group

Results

Age group	No of patients	No of procedures
Neonates	33551	40802
Infants	66708	76978
Children	81479	92416
Adults	9,3 % 17271	8,4 % 19188
All	185456	229384



Gold Standards Report

Data filter options

Age groups:

- Adults

Results

Number of patients: 17271

Number of procedures: 19188

Number of deaths (30 day): 366

Mortality (30 day): 2.12%

Number of deaths (hospital): 386

Mortality (hospital): 2.23%

	No of cases	% of all	Min	Mean	Stddev	Max
IPPV (hour)	9815	51.15	1	22.45	84.90	2232
CPB time (min)	16083	83.82	2	116.51	74.25	998
Aortic X time (min)	13646	71.12	1	74.23	49.62	540
Circulatory arrest (min)	444	2.31	1	25.91	22.26	100
Weight (kg)	19051	99.29	0.87	67.95	16.52	190
Age at operation (month)	19188	100	219	440.69	182.44	1275
LOS (day)	19188	100	0	11.09	13.03	375



Mortality vs. Procedure

Data filter options

Age groups:

- Adults

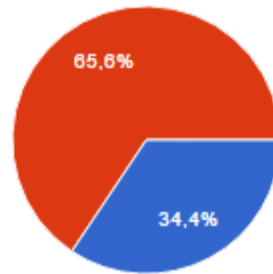
Results

Primary Procedure Name	All	30-day Deaths	30-day Mortality	Hospital Mortality
ASD repair, Patch	3237	15	0.46%%	0.50%%
Valve replacement, Aortic (AVR), Mechanical	1051	11	1.06%%	1.06%%
VSD repair, Patch	1022	9	0.88%%	0.98%%
ASD repair, Primary closure	926	15	1.62%%	1.62%%
Valve replacement, Pulmonic (PVR)	906	15	1.66%%	1.88%%
Pacemaker procedure	649	3	0.54%%	0.54%%
Conduit placement, RV to PA	647	12	1.86%%	1.86%%
Aortic root replacement, Mechanical	493	13	2.67%%	2.87%%
Valvuloplasty, Mitral	493	3	0.62%%	1.86%%
Aortic aneurysm repair	461	3	0.66%%	1.09%%
AVC (AVSD) repair, Partial (Incomplete) (PAVSD)	452	3	0.66%%	0.66%%
PAPVC repair	402	4	1.00%%	1.25%%
Aortic stenosis, Subvalvar, Repair	364	5	1.38%%	1.38%%
Valve replacement, Mitral (MVR)	343	25	7.42%%	9.20%%
Pacemaker implantation, Permanent	331	7	2.13%%	2.44%%
Conduit reoperation	327	9	2.78%%	3.09%%
Mediastinal exploration	325	26	9.39%%	10.11%%
Valve replacement, Aortic (AVR), Bioprosthetic	319	5	1.57%%	1.57%%
Valvuloplasty, Tricuspid	299	5	1.69%%	2.03%%
Valve replacement, Tricuspid (TVR)	245	18	7.53%%	9.21%%
Valvuloplasty, Aortic	233	2	0.87%%	0.87%%
Aortic root replacement, Valve sparing	187	1	0.53%%	0.53%%
PFO, Primary closure	170	4	2.35%%	2.35%%
Ebstein's repair	164	6	3.70%%	5.56%%
Coarctation repair, Interposition graft	161	2	1.24%%	1.24%%
VSD repair, Primary closure	152	2	1.32%%	1.32%%



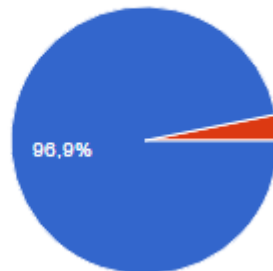
ECHSA GUCH questionnaire, September 2016

1. What is the age limit for “children” in your country?



- | | | |
|-------------------|----|-------|
| a. Below 16 years | 11 | 34.4% |
| b. Below 18 years | 21 | 65.6% |

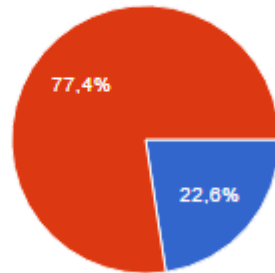
2. Do you personally operate on GUCH patients?



- | | | |
|--------|----|-------|
| a. Yes | 31 | 96.9% |
| b. No | 1 | 3.1% |



3. If yes, are these operations performed:



- a. in pediatric hospital 7 22.6%
- b. in center for adults 24 77.4%

4. What is the annual volume of congenital heart operations (CPB and non-CPB together) in your center?

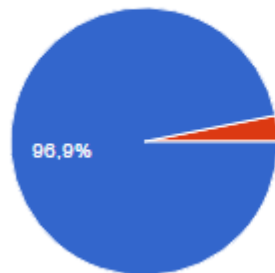
Min	Mean	Max
150	405	800



5. What is the annual volume of GUCH patients (CPB and non-CPB together) in your center?

Min	Mean	Max
20	68,3	275

6. Are GUCH patients operated upon by:



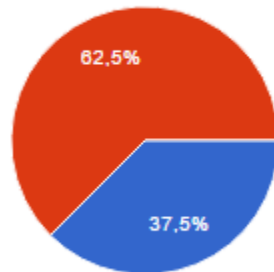
- a. Congenital heart surgeon 31 96.9%
- b. Cardiothoracic surgeon for adults 1 3.1%



7. How many GUCH operations do you personally perform per year?

Min	Mean	Max
10	36,9	150

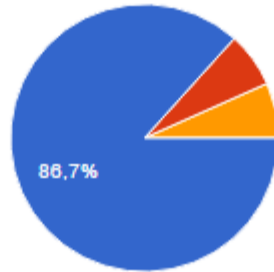
8. Who looks after your GUCH patients?



- a. Pediatric cardiologist **12** 37.5%
- b. Cardiologist for adults **20** 62.5%



9. How frequently on average GUCH patients are seen in your outpatients clinic?



- a. Once a year 26 86.7%
- b. Every second year 2 6.7%
- c. Less frequently 2 6.7%

10a. How frequently are seen patients after: Arterial Switch Operations

Min	Mean	Max
1	3,29	16

10b. How frequently are seen patients after: Fontan operation

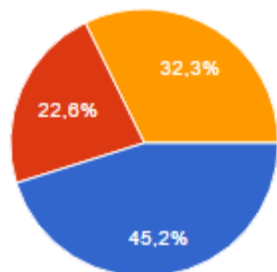
Min	Mean	Max
0,5	3,42	20

10c. How frequently are seen patients after: RV – PA conduit

Min	Mean	Max
1	3,89	30

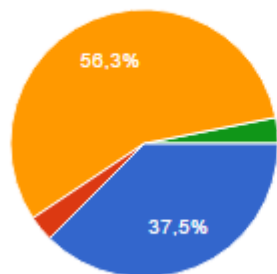


11. Do you follow your ASO patients by:



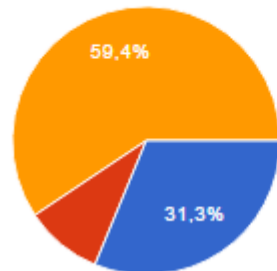
a. ECHO only	14	45.2%
b. ECHO + CT scan	7	22.6%
c. ECHO + MRI	10	32.3%
d. ECG Holter	0	0%

12. Do you follow your Fontan patients by:



a. ECHO only	12	37.5%
b. ECHO + CT scan	1	3.1%
c. ECHO + MRI	18	56.3%
d. ECG Holter	1	3.1%

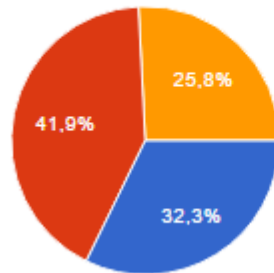
13. Do you follow your patients after RV – PA conduit by:



a. ECHO only	10	31.3%
b. ECHO + CT scan	3	9.4%
c. ECHO + MRI	19	59.4%
d. ECG Holter	0	0%

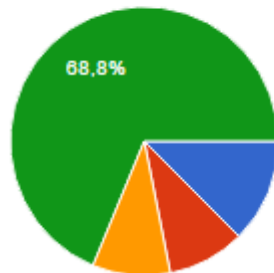


14. Optimal (ideal) set up for GUCH program should be as follows:



a. In pediatric hospital	10	32.3%
b. In hospital for adults	13	41.9%
c. Doesn't matter	8	25.8%

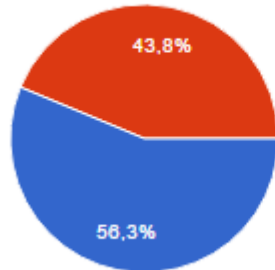
15. Leading doctor should be:



a. Pediatric cardiologist	4	12.5%
b. Cardiologist for adults	3	9.4%
c. Congenital Heart Surgeon	3	9.4%
d. Team approach	22	68.8%

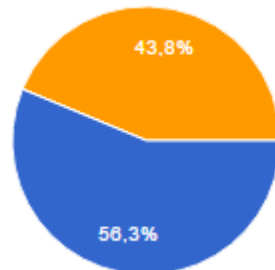


16. Would you like to see your GUCH patients personally?



- a. Yes 18 56.3%
- b. No 14 43.8%

17. Who should operate on GUCH patients?



- a. Congenital Heart Surgeon 18 56.3%
- b. Cardiothoracic Surgeon for adults 0 0%
- c. Both should be involved 14 43.8%



Important comments (1)

- Adults (>16 y) can only be treated in an adult hospital but we have Adult Congenital Cardiologists who exist as a sub-specialty of adult cardiology and have to have a job-plan that is predominantly involved in looking after ACHD patients.
- Surgery is done only by 'congenital cardiac surgeons', ie by teams of surgeons who do both the paediatric cases and the adult congenital cases.
- There are strictly designated centres where the ACHD surgery is done. This can be a hospital that has both children and adults under one roof (eg Southampton, Evelina (Guy's) or Leeds) or in a linked pair of adult and children's units (eg GOSH and Barts in London or Birmingham Children's and University Hospital Birmingham).
- The day-to-day care tends to be managed by the ACHD cardiologists who also do almost all the out-patient follow-up.
- Surgical centres should have at least 4 ACHD cardiologists. There are also 'level 2' centres that don't do any surgery but have adult cardiologists who have an interest in ACHD and will do some of the local follow-up and investigation.



Important comments (2)

- I just wanted to precise that we are a Cardiothoracic centre with both adults and children treated here even though in different units. For ACHD patients, they are looked after by specific adult congenital cardiologists (who are neither paediatric cardiologists nor regular adult cardiologists).
- This vertical model seems to me like a very good setting for these patients as all resources are concentrated here (medical, surgical and adult cardiac surgery and interventional and EP cardiology if needed)

Olivier Ghez, Royal Brompton Hospital,
London, UK



Important comments (3)

- The GUCH unit is formed by 3 Cardiologist (adult trained) which further specialized in GUCH, one dedicated electrophysiologist, one chief surgeon. There are also dedicated psychologist and in our institution is based one of the largest GUCH patient association in Italy that work closely with us (AICCA association). We also have a transition clinic for patients going from childhood to adulthood.
- The Department have acquired adult, pediatric and GUCH surgery then when multidisciplinary team is required different specialized surgeon will operate as a single team.

Mauro Lo Rito, San Donato Milanese, Italy



Many thanks for all European Colleagues who kindly responded

1. Julie Cleuziou – Germany
2. Mark Hazekamp – Netherlands
3. Alexander Kadner – Switzerland
4. Katrien Francois – Belgium
5. Morten Helvind – Denmark
6. Zsoltan Prodan – Hungary
7. Giovanni Stellin – Italy
8. Álvaro González Rocafort – Spain
9. George Sarris – Greece
10. Håkan Berggren – Sweden
11. David Barron - UK
12. Tjark Ebels – Netherlands
13. Olivier Ghez – UK
14. Simone Speggorin – UK
15. Stojan Lazarov – Bulgaria
16. Rene Pretre - Switzerland
17. Juan-Miguel Gil-Jaurena – Spain
18. Jose Maria Caffarena Calvar – Spain
19. Bernard Kreitman – France
20. Sertac Cicek – Turkey
21. Altin Veshti – Italy
22. Lorenzo Galetti – Italy
23. Ilya Yemets – Ukraine
24. Jurgen Horer – France
25. Numan Ali – Turkey
26. Carin van Doorn – UK
27. Matej Nosal – Slovakia
28. Mauro Lo Rito – Italy
29. Jean Rubay – Belgium
30. Boulos Asfour – Germany
31. Emre Belli – France
32. Bohdan Maruszewski – Poland



Thank you for attention

www.echsacongenitaldb.org