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## TRANSHEPATIC CARDIAC CATHETERIZATION IN COMPLEX CONGENITAL HEART DISEASE: *WHERE THERE IS A WILL, THERE IS A WAY*

By Ralf J. Holzer, MD; Joanne Chisolm, RN; Sharon L. Hill, ACNP; John P. Cheatham, MD

### INTRODUCTION

The last 15 years have seen a remarkable increase in the spectrum of interventional techniques, and the availability of more sophisticated endovascular devices has expanded the list of potential indications for transcatheter therapy to treat or palliate congenital heart disease.

Many patients are now undergoing repetitive transcatheter procedures, and it has become clear that interventional perseverance allows us to improve the quality of life even in patients in whom the underlying diagnosis prevents us from achieving an optimum 'curative' interventional result. For example, patients with 'corrected' pulmonary atresia, ventricular septal defect and multifocal pulmonary blood supply may require ongoing palliative procedures to rehabilitate branch pulmonary artery stenosis, sometimes as frequently as on a bi-annual basis. As such, it is not surprising that interventionists encounter an increased incidence of thrombosis or obstruction of central venous access points, not infrequently preventing the standard femoral venous access and/or jugular

venous access. Transhepatic access in these patients is often the only remaining entry point to perform the indicated procedure. We, therefore, report on our institutional experience of using transhepatic access in the evaluation and treatment of patients with underlying structural heart disease.

### Methods

All pediatric cardiac catheterization procedures that utilized a transhepatic approach for central venous access, performed at Columbus Children's Hospital between March 2003 and August 2005 were retrospectively reviewed. Data extrapolated: included demographic variables (age and weight), underlying diagnosis, performed catheter procedure, indication for transhepatic access, transhepatic-technical details (access device, sheath size, tract closure technique), as well as details about procedural complications and adverse events.

### Technique

All procedures were performed under general endotracheal anesthesia. Pre-procedural investigations included chest x-ray (CXR), transthoracic echocardiography (TTE), hematocrit and hemoglobin, as well

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No	Age (years)	Diagnosis	Procedure	Indication for Access	Tract closure
1	11.37	TGA S/P Arterial switch	PA angioplasty	Bilateral FV occlusion SVC occlusion	Coils (x2)
2	6.27	Prematurity, BPD ASD (Figure 2)	ASD occlusion with 24 mm ASO	Bilateral FV occlusion Preferred access over IJV	AVP (6mm)
3	1.44	Prematurity, PHTN ASD	ASD occlusion with 8 mm ASO	Bilateral FV occlusion Preferred access over IJV	AVP (4mm)
4	2.08	DORV, PS Mitral atresia, HLH S/P Glenn	Diagnostic catheterization	Bilateral FV occlusion	Coil
5	0.29	Unbalanced CAVSD S/P Hybrid stage I S/P Heart transplant	Angioplasty of IV Angioplasty of SVC	Bilateral FV occlusion Thrombosis RSV SVC stenosis	Coil
6	0.32	Unbalanced CAVSD S/P Stage I Hybrid S/P Heart transplant	Transhepatic Broviac	Bilateral FV occlusion Thrombosis RSV SVC stenosis	N/A
7	0.33	Truncus arteriosus Absent RPA MAPCAS to right lung S/P Unifocalisation	Angioplasty of MAPCA	Bilateral FV occlusion Preferred access over IJV	Coil
8	4.75	Pulmonary atresia VSD	Diagnostic catheterization	Bilateral FV occlusion LIJV occlusion	Coil
9	0.18	HLHS S/P Hybrid stage I	Atrial septoplasty with cutting and static balloon	Bilateral FV occlusion Preferred access over IJV	Coil
10	0.60	Truncus arteriosus S/P Truncus repair	PA angioplasty PA stent implantation	Thrombosis of all central venous access points	Coil
11	1.34	Truncus arteriosus S/P Truncus repair	PA angioplasty PA stent re-dilatation	Thrombosis of all central venous access points	AVP (4mm)
12	11.15	Truncus arteriosus S/P Truncus repair Residual RVOTO	PA angioplasty PA stent implantation	Bilateral FV occlusion Preferred access over IJV	AVP (8mm)
13	13.49	PAIVS S/P Fontan	Occlusion of veno-atrial collateral	Obstructed IVC Preferred access over IJV	AVP (4mm)
14	3.39	TGA, VSD, PS Hypoplastic RV S/P Fontan	Occlusion of excluded left medial hepatic vein	Selective access to left medial hepatic vein	Coil
15	2.34	PAIVS S/P RMBTS S/P RVOT patch RPA stenosis	PA angioplasty PA stent implantation ASD occlusion with 6 mm ASO	Bilateral FV occlusion Preferred access over IJV	AVP (6mm)
16	0.04	HLHS S/P Hybrid stage I PDA stent occlusion	Stenting of PDA	Bilateral FV occlusion Preferred access over IJV	Coil
17	0.42	HLHS S/P Hybrid stage I	Stenting of atrial septum	Bilateral FV occlusion Preferred access over IJV	Coil
18	1.65	PA, VSD S/P Rastelli type repair	PA angioplasty	Absent hepatic segment of IVC	AVP (6mm)
19	3.52	TGA PHTN	Diagnostic catheterization	Bilateral FV occlusion H/O SVC thrombectomy	Coil
20	10.97	Prematurity Truncus arteriosus S/P Truncus repair	PA angioplasty PA stent implantation	Bilateral FV stenosis Preferred access over IJV	AVP (6mm)
21	9.24	TGA S/P Arterial switch	PA angioplasty PA stent implantation	Bilateral FV occlusion RIJV, LSCV obstruction	AVP (6mm)
22	0.94	AP window S/P Repair PA stenosis	PA angioplasty PA stent implantation	Bilateral FV occlusion SVC thrombosis	Coil
23	9.20	PA, VSD S/P Rastelli type repair	PA stent re-dilation	Bilateral FV occlusion Preferred access over IJV	AVP (6mm)
24	16.79	ASD	ASD occlusion with 26 mm ASO	Bilateral FV occlusion Preferred access over IJV	Coil

Table 1. Basic details of patients requiring transhepatic access.

- AVP – Amplatzer vascular plug
- S/P – status post
- H/O – history of
- TGA – transposition of the great arteries
- BPD – bronchopulmonary dysplasia
- ASD – atrial septal defect
- PHTN – pulmonary hypertension
- DORV – double outlet right ventricle
- PS – pulmonary stenosis
- HLH – hypoplastic left heart
- CAVSD – complete atrioventricular septal defect
- RPA – right pulmonary artery
- MAPCA – major aortopulmonary collateral
- VSD – ventricular septal defect
- RVOTO – right ventricular outflow tract obstruction
- PAIVS – pulmonary atresia intact ventricular septum
- RMBTS – right modified Blalock Taussig shunt
- PA – pulmonary atresia
- FV – femoral vein
- IJV – internal jugular vein
- IVC – inferior caval vein
- SVC – superior caval vein
- IV – innominate vein
- LSVC – left superior caval vein

as activated clotting time (ACT). After sterile draping, vascular access was obtained using either a subcostal anterior axillary approach, or an intercostal midaxillary approach, with the puncture site being identified under fluoroscopy guidance. Percutaneous puncture was performed using either a 21 or 22 Gauge Chiba needle (Cook, Inc., Bloomington, IN). The needle was aimed at about 20-30 degree angle pointing towards the patient's left shoulder and introduced about 2/3 distance between outer chest wall and spine. The stylet was removed, and the needle gently withdrawn with small injections of diluted non-ionic contrast until contrast was seen to enter a hepatic vein. A 0.018" guidewire was introduced via the Chiba needle into the hepatic vein and right atrium. The tract was dilated using the 'micropuncture' kit where appropriate, and the wire exchanged to accommodate the sheath that was initially required for the procedure (median diameter: 6Fr). If the patient size permitted, a special angulated transhepatic sheath was used (Cook, Inc., Bloomington, IN). Once transhepatic access was obtained and an arterial line inserted to monitor blood pressure during the procedure, the patient was fully heparinized to maintain an activated clotting time (ACT) above 200 seconds.

After completion of the diagnostic or interventional catheter procedure, the hepatic tract was occluded using either coils or the Amplatzer vascular plug (AGA Medical, Golden Valley, MN). Particular care was taken to place the coil or device inside hepatic tissue rather than inside the hepatic vein, which would risk embolization of the device or coil. To facilitate appropriate placement of the coil/device, the catheter/sheath is withdrawn under gentle injection of nonionic contrast to deter-

mine the point at which the hepatic vein is exited. To avoid bleeding from additional hepatic veins or arteries that were inadvertently perforated when inserting the Chiba needle with stylet, the catheter/sheath is further withdrawn to sit just underneath the hepatic capsule before deploying the occlusion device/coil.

After completion of the procedure, the patient is routinely monitored for 24 hours with specific attention to abdominal distention and/or any evidence of hemorrhage. Additionally, investigations performed the following day included a CXR and, if indicated, an ECG and transthoracic echocardiography.

### Results

Twenty-four cardiac catheter procedures requiring transhepatic access were performed in 22 patients between March 2003 and August 2005. The median age at the time of procedure was 26.5 months, ranging from 15 days to 16.7 years. The youngest patient required

hybrid palliation of hypoplastic left heart syndrome. The median weight was 11.5 kg, ranging from 2.0 to 65.8 kg. Indications for using transhepatic access included thrombosis of bilateral femoral venous access in thirteen patients, thrombosis of bilateral femoral venous access as well as internal jugular / superior caval venous access in eight patients, obstructed or absent hepatic segment of inferior caval vein in two patients, as well as selective left middle hepatic venous access in one patient. In all patients with isolated bilateral femoral venous occlusion, transhepatic access was preferred over jugular venous access for a more optimal approach to intraatrial septum or pulmonary arteries in small patients. No more than three attempts were necessary to percutaneously enter a hepatic venous vessel in patients. Ultrasound guidance was not routinely used with the exception of one patient with Fontan-type circulation, in whom an excluded left middle hepatic vein was selectively occluded using ultrasound guided selective access, assisted by our interventional radiology colleagues.

Underlying diagnosis and performed procedure(s) are listed in Table 1. All patients had underlying structural heart disease. Transcatheter interventions were performed in 21/24 (87.5%) patients, including occlusion of an intraatrial communication in four patients, and rehabilitation of branch pulmonary artery stenosis in ten patients, six of which included placement of one or more endovascular stent(s). Other procedures performed in one patient using the transhepatic route included: angioplasty of central venous vessels, angioplasty of collaterals, coil occlusion of collaterals, Broviac catheter placement, (cutting/static) balloon septoplasty as well as stenting of intraatrial septum and a persistent arterial duct.

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***"Many patients are now undergoing repetitive transcatheter procedures and it has become clear that interventional perseverance allows us to improve the quality of life even in patients in whom the underlying diagnosis prevents us from achieving an optimum 'curative' interventional result."***

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transhepatic access as early as 15 days of age, because of bilateral femoral venous occlusion after previous stage I



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The median sheath size used was 7Fr, ranging from 5Fr to 14Fr. The transhepatic tracts were occluded using endovascular coils in 13 patients and the Amplatzer Vascular Plug (Amplatzer Medical Sales, Golden Valley, MN) in 10 patients (4mm device: n = 3, 6mm device: n=6, 8mm device: n=1).

#### Adverse events

Second or third degree AV block was encountered during three procedures, associated with placement of the transhepatic sheath. All three patients had a weight of less than 5kg, and in two of these three procedures, heart block was directly related to sheath/wire protruding through the tricuspid valve while positioning the sheath. All but one occurrence of heart block resolved very quickly. However, in one patient heart block persisted, and the patient eventually required implantation of an epicardial pacemaker during the same admission. In another case, adrenaline and chest compressions were briefly required to stabilize the patient.

Three patients required blood transfusion, neither of which was directly related to transhepatic access itself. A patient who underwent selective occlusion of the excluded left medial hepatic vein after transcatheter Fontan completion for an outside institution, had transiently elevated liver enzymes. In one patient, a pneumothorax was identified towards the end of the catheter procedure. The pneumothorax eventually required insertion of a pigtail catheter but the etiology appeared to be unrelated to the catheter procedure itself.

#### DISCUSSION

The increasing use of transcatheter therapy in patients with congenital heart disease has resulted in a situation where an increasing number of patients

have multi-level obstruction of central venous access points, necessitating the use of transhepatic access. Procedures using transhepatic access have to be performed often repeatedly in the same patient. Book and colleagues for example reported on two pediatric cardiac transplant patients in whom transhepatic access was used for endomyocardial biopsy as often as five times.[1]

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***“...transhepatic access is a safe technique for central venous access that should also be considered in selected cases when other central venous access points are still available, specifically when the atrial septum has to be approached or when rehabilitation of branch pulmonary artery stenosis is intended.”***

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However, while transhepatic access has been regarded in the past as an access route reserved for those cases in which other means of central venous access are not available, we now recognize that many interventional techniques may have additional benefits derived from the elective use of transhepatic access. The approach to the intraatrial septum from an internal jugular venous route is suboptimal and device closure using this route is technically extremely difficult at best, and may even be impossible especially in very small patients. Even with patent femoral veins, transhepatic access may be worth a consideration due to the more perpendicular approach to the atrial septum, especially when failing

to securely place a device using the femoral venous route. Additional benefits of the transhepatic route may be seen when palliating branch pulmonary artery stenosis, especially in the presence of bilateral femoral venous occlusion, due to the more direct course to the right ventricular outflow tract. As early as 1999, Shim and colleagues reported on elective transhepatic access in patients with patent femoral venous access, to facilitate rehabilitation of branch pulmonary artery stenosis or device closure of secundum atrial septal defect.[2,3] The availability of transhepatic access is obviously not limited to evaluation and treatment of structural heart disease. Fischbach and colleagues reported on two patients in whom an accessory-pathway mediated tachycardia was successfully ablated using transhepatic access.[4]

Transhepatic access procedures, when performed carefully, have limited and rare complications. In most series, the incidence of significant complications related to transhepatic access is less than 5%, even though it is difficult to establish accurate figures due to the small series reported in the literature.[3,5] They include pneumothorax, intra-/retroperitoneal bleed, hepatic abscess, injury to gall bladder or bowel, portal vein thrombosis, cholangitis and peritonitis.

In our own series, a small pneumothorax was observed post procedure in one patient, the cause of which was probably unrelated to the procedure itself, even though transhepatic access with the needle inadvertently entering the pleural space could not completely be ruled out as a cause. It is difficult to establish in hindsight, whether transhepatic access was responsible for the occurrences of heart block in three pa-



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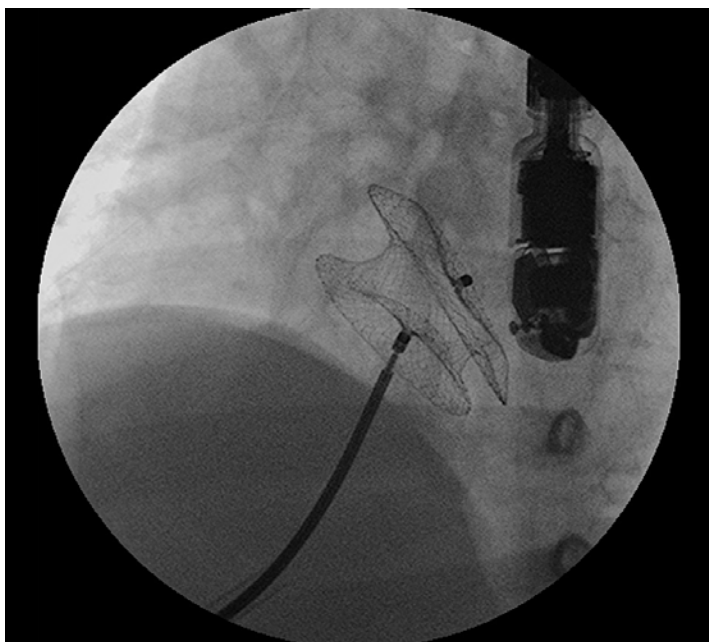


Figure 1. Transhepatic occlusion of a secundum atrial septal defect in a 6 year old patient using the Amplatzer septal occluder.



Figure 2. Placement of a 6mm Amplatzer vascular plug (arrow) for occlusion of the transhepatic tract in a nine year old patient who underwent pulmonary artery rehabilitation (stent placement).

tients, as this complication can be observed not infrequently in many catheter procedures undertaken in small infants. All other encountered complications were not specifically related to transhepatic access.

Sommer and colleagues reported on a series of twelve transhepatic catheter procedures that were performed without any significant procedure-related complication.[5;6] Shim and colleagues reported on a series of 30 transhepatic catheter procedures with one significant complication being an intraperitoneal bleed necessitating explorative laparotomy in a two months old infant [3] and Erenberg and colleagues described two isolated cases of intraabdominal bleeding associated with transhepatic cardiac catheterization.[7] In 2005, McLeod and colleagues reported on a small series of five patients undergoing transhepatic car-

diac catheterization.[8] A retroperitoneal bleed was observed in one patient secondary to the use of thrombolysis because of loss of femoral arterial pulse.[8]

The preferred technique of obtaining transhepatic access in our series was a subcostal / anterior axillary approach. However, the lateral, mid-axillary approach, as described by Shim and colleagues can be used as a suitable alternative[2], as was the case in some of our patients. Its advantages include a lesser likelihood of injury to gall bladder or intra- and retroperitoneal bleed, as well as a shorter course to the right atrium, which allows the use of short haemostatic sheaths even in slightly bigger patients. However, the subcostal approach has the advantage of a more direct course to the right atrium, as well as avoidance of the sometimes painful injury to the pleura and pleural space.

We do not routinely use pre-and post-procedural screening of hepatic enzymes and abdominal ultrasound, but emphasize the need for close post-procedural observation for the occurrence of abdominal distention or hemorrhage.

The availability of the Amplatzer Vascular Plug (AGA Medical, Golden Valley, MN) has significantly expanded the spectrum of suitable closure methods to be used for occlusion of the transhepatic tract (Figure 1). It is important though to highlight that the technique of withdrawing the sheath under continuous aspiration to determine the exact location when the hepatic vein is exited is notoriously unreliable, especially when largesized sheaths were being used which create a larger transhepatic tract that may remain in communication with the en-



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tered hepatic vein. We therefore, advocate the use of continuous injection of small amounts of contrast while withdrawing the sheath as a more reliable way of determining when the hepatic vein is exited.

Ultrasound guidance may further facilitate the procedure, even though it is our opinion, that this should be reserved for anatomically difficult cases where, for example, a specific hepatic vein is intended to be entered, such as in case 14 of this series (Table 1). Johnston and colleagues reported on a series of 12 catheterizations in whom ultrasound guidance was successfully used to facilitate a subcostal transhepatic approach, without encountering any access-related complications or adverse events.[9]

As a summary, transhepatic access is a safe technique for central venous access that should also be considered in selected cases when other central venous access points are still available, specifically when the atrial septum has to be approached or when rehabilitation of branch pulmonary artery stenosis is intended. The overall rate of access-related complications is low and therefore, transhepatic access should form an essential ingredient to the armamentarium of interventional skills.

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## HEART SAVING PROJECT: CATHETER INTERVENTION IN MONGOLIA

By Noriyuki Haneda MD; Hideshi Tomita, MD

Since October 2001, members of a group Japanese pediatric cardiologists, have gone to Mongolia once or twice a year to do diagnostic and interventional catheterizations. We were invited to do that by Dr. Enkhsaikhan from the State Research Center on Maternal and Child Health in Mongolia. In her words, "The surgical outcome of congenital heart disease is quite poor in Mongolia. The mortality and morbidity of open heart surgery is quite high, while even for PDA ligation, a large residual shunt is common and a patient occasionally dies because of ligation of the left pulmonary artery."

Considering the limited medical resources available in Japan for this project and limited resources in Mongolia, as well as cost, risk and benefit, we decided to focus our activities on screening by echocardiography, transcatheter closure of PDA, balloon dilatation of pulmonary stenosis (PS) and coarctation (CoA), and diagnostic catheterization. Furthermore, PDA is a special problem in Mongolia because of the high altitude. For the first visit, from October 3rd - 13th 2001, two pediatric cardiologists and a medical engineer went to Mongolia carrying all the medical supplies for transcatheter closure of PDA with coils and balloon catheters. Transportation, as well as the cost of medical supplies, was donated by the Japanese people.

We successfully closed 5 cases of PDA in the first visit in the operating room of the State Research Center on Maternal and Child Health using fluoroscopy with a portable X-ray machine for the gastrointestinal tract; it is the only fluoroscopy machine in that center (Figure 1). There was no Cine, no Video, nor any other X-ray recording or replaying equipment. We judged the size and morphology of the PDA by rapid hand injection.

### Volunteers in the Heart Saving Project in Mongolia:

Kenji Kuroe, MD; Shunji Nogi, MD; Hideaki Ueda, MD; Kenji Kishida, ME; Takashi Higaki, MD; Yasunori Horiguchi, MD; Jun Furui MD; Masamichi Tamura, MD; Hidemi Takata MD; Fumitoshi Tsurumi, MD; Kenji Yasuda, MD; Shinichiro Tanaka, MD; Hiroshi Yano; Akiko Masukawa; and Namiko Takeda.



Figure 1. Operating room and portable X-ray machine of the State Research Center on Maternal and Child Health.

Up to 2005, we have visited Mongolia six times, while additional members have volunteered to join us from all over Japan, including doctors, medical engineers, nurses, laboratory technicians, and medical students. For the first two visits, and the first half of the third visit, all our activities, which include screening with echo, and both diagnostic and interventional catheterizations, were done in the State Research Center on Maternal and Child Health. From the latter half of the third visit, we moved to the Shastin Central Clinical Hospital, which is an adult cardiology and cardiovascular surgery center, and has the only cine angiography machine in Mongolia, to do catheterizations. Until the fourth visit the cine-angio machine was an old Hitachi with poor resolution (Figure 2, left). However, since the fifth



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Figure 2. Old (left) and new (right) cath lab of the Shastin Central Clinical Hospital.

visit in 2004, it has been upgraded to a relatively new Philips with satisfactory resolution (Figure 2, right). Until the fifth visit, we used only coils, 0.052 inch coils, Flipper coils, Gianturco coils, or Platinum coils, for closing a PDA. The Amplatzer PDA occluder was introduced for the first time during the sixth visit in 2005, thanks to AGA and Dr Larry Meng from China.

During the first six visits, around 500 patients were given an echo examination, while 98 patients were diagnosed as having a PDA. Among these, 94 patients had an indication for closure, while in four patients closure was contraindicated because of Eisenmenger syndrome or active endocarditis. During the first five visits, when we used only coils for PDA closure, there were 59 patients with PDA; however, we sent 10 patients with a large PDA to surgery. Consequently, in this

period, we attempted coil occlusions in 49 patients and achieved complete closure in 47. Initially, we considered that PDA with a diameter less than 6 mm was suitable for coil occlusion, as the largest coil we had was a 0.052 inch Gianturco coil with a loop diameter of 12 mm. However, we were able to close a PDA with a minimal diameter of 8 mm with 14 coils (Figure 3). In this period, 25 patients of PDA < 3.5 mm could be closed with 3 or fewer coils (Figure 4). Of 14 patients of 3.5 mm PDA to  $\leq$  4.5 mm, 3 were complicated by migration. However, all migrated coils were retrieved, and we were finally able to deploy coils with complete occlusion. In 10 patients with a PDA > 4.5 mm, 3 were complicated by migration, while in 2 patients we finally abandoned the procedure and sent them to surgery. Even in the 8 patients where we could deploy coils, 4 or



Figure 3. The largest PDA (8 mm) closed with 14 coils.

more coils were required for closure. Consequently, we decided to introduce the Amplatzer PDA occluder, considering the high risk and cost of coil occlusion in patients with a PDA  $\geq$  3.5mm.

In the sixth visit from 28th July to 7th August 2005, we closed 20 patients with PDA (2.5-2.9 mm, 2 patients; 3.0-3.5 mm, 3 patients; 3.5 mm  $\leq$ , 15) with the Amplatzer, while 15 patients with a PDA < 3.5 mm were closed with coils. The largest PDA with a minimal diameter of 10 mm, which we believe was hard to close with coils, was closed safely with an Amplatzer duct occluder 14/16 (Figure 5). We believe the Amplatzer PDA occluder is very suitable for use in developing countries where surgery has serious morbidity and mortality, since it is user-friendly, safe, and needs less procedure time. Furthermore, it is more cost-effective than coil occlusion in a PDA  $\geq$  3.5mm.

In the total 6 visits, we closed PDA's in 82 patients. Interventional catheterizations, other than PDA occlusion, included 10 patients with balloon dilatation for PS, 2 patients for CoA, and 1 patient each of combined coil occlusion for PDA and bal-

Pediatric Cardiac Intensive Care Society (PCICS) and Congenital Cardiac Anesthesia Society (CCAS) present

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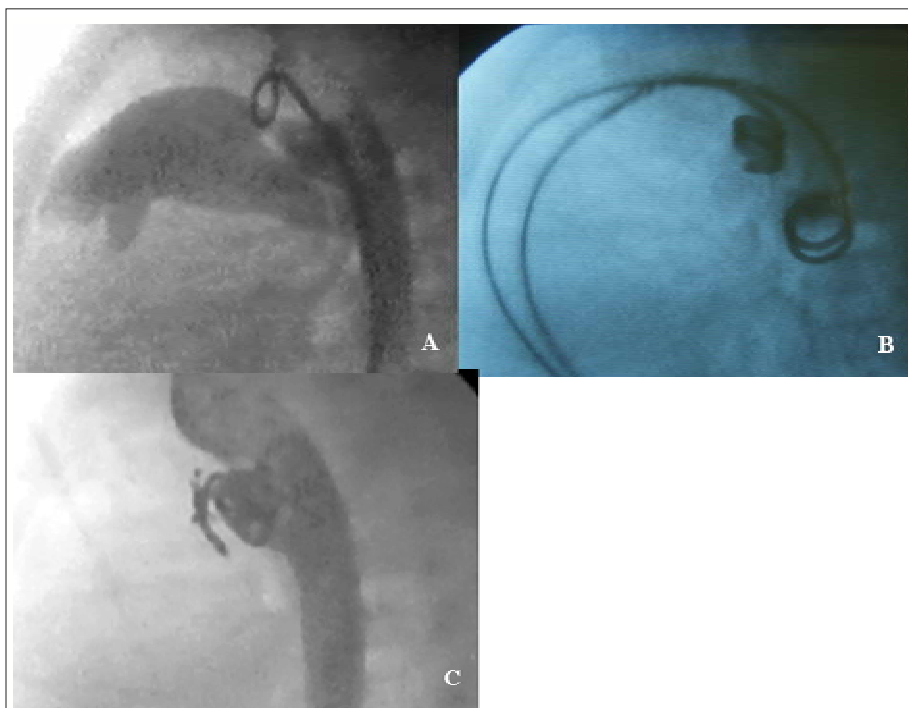


Figure 4. PDA with a minimal diameter of 3.2 mm closed with 3 coils.

[A] Lateral projection of aortogram; [B] Simultaneous deployment of two "0.052 coils (MWCE-52-10-8 and MWCE-52-8-6); [C] Complete closure was documented by angiogram after additional deployment of MWCE-38-7-5.

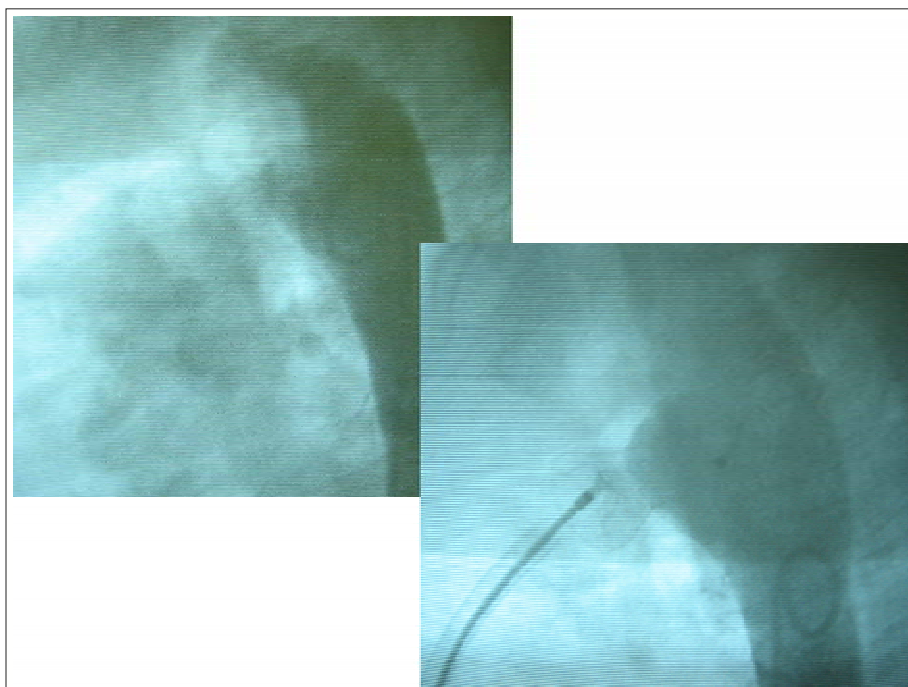


Figure 5. The largest PDA in the 6th visit (10 mm) closed with an Amplatzer duct occluder 14/16.

loon dilatation for CoA; and retrieval of an intravascular foreign body. We are consider-

ing introducing the Amplatzer VSD occluder to our project in the near future,

taking into account the feasibility of the procedure and the needs of the interventional catheterization.



Author: (Arrow) N. Haneda, MD, next to N. Haneda, and H. Tomita, corresponding author.

The first purpose of our project is to help as many as children possible with heart disease; however, our final goal is to develop pediatric cardiology in Mongolia so that Mongolian people can help children with a heart disease by themselves. Consequently, we attach a great deal of importance to the education of Mongolian doctors and to health screening in rural areas.

~CCT~

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## 4TH WORLD CONGRESS OF PEDIATRIC CARDIOLOGY AND CARDIAC SURGERY

It was a great pleasure for the Argentine community of pediatric cardiologists and cardiac surgeons to host the Fourth World Congress of Pediatric Cardiology and Cardiac Surgery in beautiful Buenos Aires last September.

It was shared by 3008 delegates from all over the world in a friendly atmosphere at the Buenos Aires Sheraton Hotel.

The Scientific Programme included 7 Plenary Sessions with overviews of new and exciting developments in our speciality, 19 Controversies on hot issues, 6 named conferences as a tribute to, and in recognition of our pioneers, and 48 Symposia which allowed hard discussions about all the aspects of pediatric cardiology.

A distinctive feature of the scientific programme has been the inclusion of many special symposia endorsed by scientific societies or institutions who shared with the world the state-of-the-art of their practice and their point of view on specific academic subjects of interest.

We are indebted to the honorary presidents and the distinguished international faculty who have enlightened the scientific programme and warranted the congress's success.

The Nursing Programme enhanced the academic attraction of the event.

We must express our sincere acknowledgement to the Steering Committee for trusting Argentina to stage the World Congress and also to the

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***"The Scientific Programme included 7 Plenary Sessions with overviews of new and exciting developments in our speciality, 19 Controversies on hot issues, 6 named conferences as a tribute to, and in recognition of our pioneers, and 48 Symposia which allowed hard discussions about all the aspects of pediatric cardiology"***

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International Committee for their permanent input and support.

The Congress had delegates from 84 different countries, 30,5% from Europe, 41% from Latin American, 15,5% from North America, 12% from Asia and 1% from Africa.

Most represented registrants were from: Argentina - 383; Brazil - 360; USA - 313; Spain - 194; UK - 96. The total number of faculty was 316.

Over 1.500 abstracts have been reviewed and 152 selected for oral presentation and 1103 posters were exposed.

In order to organize the Congress, the Organizing Committee had 380 meetings, 55 promotional trips,

23.000 printings, 20 Newsletters with a permanent staff of 6 persons and 70 temporary staff.

There were two outstanding Pre-Congress Meetings:

- The Ninth Pediatric Interventional Cardiac Symposium (PICS IX) & Third Emerging New Technologies in Congenital Heart Surgery (ENTICHS-III)
- The Congenital Heart Surgeons Society Meeting.

Last, but not least, were the social activities. The opening ceremony began with wonderful speeches from Chairmen Horacio Capelli and Guillermo Kreutzer and the Honorary President, Jane Somerville, and ended with a Tango show and the Farewell Party at the Salón Dorado of the Colon Theater, one of the most impressive opera houses in the world.

In the Closing Plenary session, it was announced that the 5th World Congress will be held in Cairns, Australia, June 22-26, 2009. For more information: [www.pccs2009.com](http://www.pccs2009.com).

~CCT~

*The Organizing Committee:*

*Co-Chairmen: Horacio Capelli and Guillermo Kreutzer; Committee members: Horacio Faella, Christian Kreutzer, Pablo Marantz and Andrés Schlichter*

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## RECEIVING A CHILD'S DIAGNOSIS OF COMPLEX CHD: PARENTS' PERSPECTIVES AND COMMUNICATION TOOLS

By Debbie Hilton Kamm

This is first in the series of two parent articles by Debbie Hilton Kamm, the co-founder and president of California Heart Connection ([www.caheartconnection.org](http://www.caheartconnection.org)), a nonprofit support network for those with heart defects. She is the creator of the HLHS Information Page ([www.HLHSinfo.org](http://www.HLHSinfo.org)), a site for parents expecting a child with Hypoplastic Left Heart Syndrome (HLHS). She has a 5-year-old son with HLHS and Total Anomalous Pulmonary Vein Return (TAPVR) who underwent the 3-stage surgeries and vein repair.

### Introduction

When presented with their child's diagnosis of complex Congenital Heart Disease (CHD), parents are understandably emotional and often overwhelmed due to lack of knowledge of the heart condition, unfamiliarity with the terminology and medical environment, and grief over the loss of their "healthy" child. They may be intimidated to ask questions, or very often, do not even know what questions to ask. Yet, parents must quickly learn about the diagnosis and make many tough decisions including whether or not to terminate if the diagnosis occurs during pregnancy. Physicians can help parents in this situation by acknowledging their emotions, clearly communicating diagnosis-specific information, and being aware of the manner in which information is presented and interpreted by the parents.

This article is based upon hundreds of interactions with parents through: California Heart Connection, a nonprofit support network ([www.caheartconnection.org](http://www.caheartconnection.org)); The HLHS Information Page, a web site created to help parents receiving the prenatal diagnosis of HLHS ([www.HLHSinfo.org](http://www.HLHSinfo.org)); and online support forums for those with children with CHD. It is also based upon personal experience receiving a prenatal diagnosis of Hypoplastic Left Heart Syndrome (HLHS) for our now 5-year-old son. Handouts and forms referenced throughout the article have been created to help improve communication with parents at diagnosis and can be downloaded for free from the California Heart Connection web site at [www.caheartconnection.org](http://www.caheartconnection.org).

### Receiving the Diagnosis

**Setting and Emotions.** Parents appreciate having privacy and being with a spouse or loved one for support as they get the news.[1] Physicians can acknowledge the emotions by simple

statements such as, "I know this isn't what you are expecting." Or, "Let me know if you'd like to stop at any time and take a break." Having a social worker or other team member involved from the beginning who can help the parents deal with their emotions will help them absorb information on the diagnosis and treatments.

**Demeanor.** Parents sometimes don't recall hearing or understanding much of the diagnosis-specific information after the initial diagnosis is given, but they do recall the manner in which the information is presented. In fact, families often place more emphasis on how they were informed than the specific details about the condition.[1] The same information presented in different ways can also lead parents to very different conclusions, and greatly impact decision-making. Roger Mee, MD, Department Chair of Pediatric and Congenital Heart Surgery at the Cleveland Clinic, illustrates this point in the book, "Walk on Water." The message conveyed by saying, "There's a fifty percent chance we can get your child through," with an upbeat tone and a smile differs greatly from saying, "There's a fifty percent chance your child will die," with a furrowed brow and frown.[2] Physicians should be aware of the subtle messages they may be conveying by their choice of words, tone and demeanor.

**Timeframes.** Some parents leave the initial appointment at diagnosis unclear on what the next step will be. Giving parents written timeframes for any future appointments, follow-ups or tests can be helpful.

**Accessibility of Physicians.** (*Medical Specialties Form*). Having access to physicians as questions arise is important to parents. Allowing parents to e-mail physicians over non-urgent matters allows them to ask questions without "bothering" physicians during their busy work schedules. Many parents are confused by the different medical specialties; therefore, providing written descriptions and contact information for each can help parents ask appropriate questions of the correct medical professional.

**Control.** Lack of control is often mentioned as one of the most prominent feelings parents encounter when receiving their child's diagnosis. Deciding how much information to take in at one time, whether or not (or when) to pursue additional testing, and researching treatment options helps some parents feel more in control.

**Repetition.** The emotional turmoil, new terminology, and lack of knowledge on the subject may lead to many parents repeatedly asking the same questions. Some note that due to parental grief,



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fear and anxiety, retention of information about their child's condition can be as little as 20%.[3] Parents should be encouraged to ask questions, even repeatedly, to help them absorb the information.

### Prenatal Diagnosis

Amniocentesis. Parents receiving a prenatal diagnosis of CHD are sometimes urged to make an immediate appointment for an amniocentesis. Some parents recall the amniocentesis being performed before they had time to consider the possible risks and benefits of the procedure. Others have been told that the results could somehow change the course of treatment, only to find out later that was not true for their child's condition. Parents should be given time to digest the information given at the time of diagnosis, and weigh the risks and benefits of amniocentesis for their particular situation. Allowing this time can make parents feel more in control of the process, and can help them to make more informed decisions.

Continuing the pregnancy. Many parents report great shock and sadness at the mention of termination at diagnosis, interpreting that to mean the condition is fatal or that it is the recommended course of action. Many parents will want to weigh all of the factors involved such as the seriousness and accuracy of the diagnosis, potential treatments and prognosis prior to deciding whether or not to continue the pregnancy. However, time to make these decisions is often very limited. Some parents may also consider putting the child up for adoption, while others may be more willing, or able, to handle a child with medical needs. [4]

For many parents the decision often boils down to a simple question: "What can I live with?" Some could not live with the idea of putting a child through surgery, or with the unknowns of having a child with CHD. Others can only live with themselves knowing they did everything possible for their child. Receiving the diagnosis of a child's CHD is a life-altering experience for parents, no matter what course of action they choose, or what the final outcome may be.

### Diagnosis-specific Information

Prepared handouts. Many parents state that printed materials were critical in helping them to understand the diagnosis and treatments. Those who don't receive any printed handouts often leave the office confused, and may not accurately remember what they have been told. Clearly labeled printed diagrams of the normal heart and of the specific defect are beneficial in helping parents understand the condition. Hand-drawn diagrams are often confusing, but may be necessary if the anatomy is unique. Having clear visual aids helps parents follow the physician's explanation of the defect, and allows them to review the information once at home.

Levels of Information. Physicians may wish to offer information in levels, starting with basic information on the normal heart to set the stage for parents and act as a review for those who have not recently studied the heart. Basic information on the specific heart defect can then be presented, followed by more detailed descriptions of the anatomy, and how it affects the child. Some parents may wish to review the detailed information immediately with the physician; some may prefer to review the printed information later.

Physicians can ask parents directly how much information they want during the initial diagnosis, and if they would like to stop at any point.

Internet Resources. (*Internet Resources Handout*). Many parents access the Internet for more information, especially if not given written materials at the time of diagnosis. Physicians can help guide parents to reputable Internet resources which provide accurate information; however, even very reputable websites can have outdated or misleading information on a specific diagnosis. Therefore, physicians should review web sites and other information prior to referring parents to them to avoid any confusion or misunderstandings of the diagnosis.

### Information for Decision-Making

Current Information. Parents sometimes state frustration that the initial information they received at diagnosis was outdated. For example, parents of children with complex CHD sometimes report that they were given a very negative prognosis at diagnosis, only to discover later that overall success rates or those at major heart centers are better than were originally quoted. In one instance, a woman grieved the loss of her baby shortly after birth, after being told no treatments existed for babies with Hypoplastic Left Heart Syndrome (HLHS). She subsequently viewed a television show that profiled HLHS survivors from infancy through their late teens and was shocked and distraught to learn that surgeries were available when her child was born. The fact that she was not given the option of surgical intervention resulted in extreme anguish, and added to her grief for the loss of her child.

Treatment Considerations. (*Hospital Contact Form and What to Ask the Surgeon/Hospital Handout*). To aid in decision-making, parents need clear information on the results of surgeries performed locally and how they compare with results in other centers.[5] Some recommend the use of quantitative tools to compare the quality of care based upon the complexity of the surgical procedures, such as the Aristotle Method.[6] This quantitative information can then be weighed along with the needs of the family's situation, insurance limitations, financial constraints and other variables. Providing a list of questions for parents to ask when considering different hospitals also allows them to weigh the individual variables based upon their own needs. Some parents, for example, may choose a hospital based upon location or services provided and not solely upon surgical experience or outcomes.

Insurance. (*Insurance Terms Handout and What to Ask the Insurance Company Handout*) Insurance considerations are one of the major concerns and source of confusion for families. Helping parents understand insurance-related terms, and providing appropriate questions to ask of the insurance company can be extremely beneficial in reducing their anxiety level and helping them with their decision-making.

Support. Connecting with other parents who have children with CHD can provide much needed support and information. Physicians may create their own patient contact list, or refer families to an established support network. Physicians are encouraged to contact support organizations to determine if the information and support provided is appropriate for their patients.

The following support organizations offer information, parent-matching and online support groups in addition to the other listed services:

- California Heart Connection – [www.caheartconnection.org](http://www.caheartconnection.org) – events, downloadable handouts and forms.
- Little Hearts, Inc – [www.littlehearts.org](http://www.littlehearts.org) – newsletter, stories, large annual picnic.
- TCHIN – [www.tchin.org](http://www.tchin.org) – portrait gallery, list of local support groups.

**Accuracy of the Diagnosis.** Parents often report that they assumed (and were not told otherwise) that diagnostic tests are 100% accurate. In the case of a prenatal diagnosis where termination may be considered, it is imperative that parents understand the potential error rate of the tests. In the case of HLHS, for example, Richard Jonas, MD, Chief of Cardiovascular Surgery and Co-Director of the Children's National Medical Center Heart Institute states: "It is important to remember, however, that although prenatal echo is sensitive to the diagnosis of HLHS, it is not highly specific and can over diagnose the problem. We have seen a number of cases where babies required only coarctation or aortic valve intervention, and on occasion, no intervention at all despite a prenatal diagnosis of HLHS."<sup>[7]</sup>

#### Presenting Balanced Views

**"Rare" Condition.** Many parents assume that "rare" means one in a million, or that it occurs so infrequently that there are no survivors of the condition. Giving quantifiable information on the incidence of the condition helps parents gain perspective on how many others have experienced it, giving them reassurance and a possible pool of resources.

**Best Case Scenarios.** The diagnosis understandably focuses on what is wrong with the child, possible risks of treatments, and possible limitations the child may have. However, parents appreciate physicians who focus on their child as a whole, rather than solely the negative aspects of the condi-

tion.<sup>[1]</sup> One family reported that after answering questions about the complications, risks, and possible negative outcomes, the physician said, "Now let me tell you about the best-case scenario." He then proceeded to talk about the children who had survived, and were living normal, active lives, which gave the family more hope and a more balanced view of the possibilities for their child.

**Personal or Professional Preferences.** Physicians' preferred treatment for a particular CHD may vary significantly based upon their views and experiences. One study showed that physicians placed greater emphasis on long-term survival with good heart function in their preferences for treatment. However, parents may use different criteria when considering treatment options. They may put more emphasis solely on short-term or medium-term survival, for example, with the hope that treatments or cures will become available in the future. The same study found that physicians who did not have direct experience with adults with a specific heart defect were more pessimistic about the outcomes for children diagnosed with that particular type of CHD.<sup>[8]</sup> Therefore, it is vital that parents understand physicians' preferences, and the reasons for them to provide context and reduce confusion upon hearing conflicting views from other physicians. Parents can then evaluate their own views and beliefs and make the decisions that are most appropriate for their situation.

**"What Would You Do?"** Seeking advice, many parents ask this question of physicians. However, a hypothetical response may not be relevant; a physician's response may be very different if his child was actually diagnosed with CHD. Many parents assume that the physician's opinion is based upon medical fact, and view the answer as a professional recommendation. They may be offended or alienated if the physician's stated course of action varies from that which the parents are considering. Therefore, a more appropriate and reasonable response to this question is: "Since I'm not in your situation, I honestly can't answer that. But, let me put you in contact with other parents who have made these tough decisions." Allowing parents to connect with others who have actually been faced with the diagnosis and have

***"This article will be a great help to physicians and parents. When explaining the diagnosis of fetal heart disease, it is important to communicate accurately and honestly, both verbally and otherwise. I do not believe that it is ever appropriate for me, as the fetal cardiologist, to recommend termination of pregnancy, or to attempt to answer the question, 'What would you do if you were me?' It is also important for parents to be connected to support organizations upon receiving a diagnosis, and I am happy to refer patients to California Heart Connection."***

***~Mark Sklansky, MD  
Director, Fetal Cardiology  
Children's Hospital  
Los Angeles***

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chosen different courses can help them gain a realistic view of the condition and what it entails. Each family can then make treatment decisions based upon their own financial situation, health insurance issues, emotional state, morals and values, and beliefs about the diagnosis and treatments.

### Conclusion

When receiving a diagnosis of complex CHD, parents must deal with a myriad of emotions while learning about the diagnosis and the treatment options. It is important for physicians to acknowledge the parent's emotions, and understand that the manner in which information is presented and interpreted by parents can greatly influence their decision-making. Physicians can help parents better understand the diagnosis by presenting clearly written information and guiding them to reputable and accurate sources of information and support. The use of the handouts and forms referenced above can help improve communication and ease the anxiety of parents receiving their child's diagnosis of CHD.

The following handouts and forms can be downloaded for free from the California Heart Connection web site at [www.caheartconnection.org](http://www.caheartconnection.org):

- Internet Resources Handout – selected online resources for heart diagrams and information on specific diagnoses of CHD
- Hospital Contact Form – a form for listing hospitals which treat the specific diagnosis.
- What to Ask the Surgeon and Hospital Handout – a list of questions to help compare hospitals.
- Insurance Terms
- What to Ask the Insurance Company Handout – a list of questions to determine specific benefits, restrictions, out-of-pocket costs, etc.
- Medical Specialties Form – a list and description of different medical specialties with space to provide contact information for each.
- Resource Guide – an important reference tool to help parents find resources and ask appropriate questions regarding how to care for their child. Includes information on support networks, medical resources, helpful products, Early Intervention services, insurance/financial information, and more.

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~CCT~



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## The Barth Syndrome Foundation

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**Symptoms:** Cardiomyopathy, Neutropenia, Muscle Weakness, Exercise Intolerance, Growth Retardation

## 8TH INTERNATIONAL WORKSHOP ON CATHETER INTERVENTIONS IN CONGENITAL AND STRUCTURAL HEART DISEASE

By Yves Bayard, MD

This year's Workshop on Catheter Interventions in Congenital and Structural Heart Disease was held at the Congress Center of Frankfurt am Main, Germany, from June 16th-18th. More than 300 attendees were able to follow over 30 live cases performed by Prof. Sievert and distinguished international faculty, and interact directly with the operators. A total of 54 didactic lectures were given during the workshop, presenting emerging technologies and state of the art knowledge in various fields of congenital and structural heart disease. Daily lunchtime symposia according to the motto "step by step and tips and tricks" were held by the most experienced specialists for different interventions.

A unique feature following the congress was the optional hands-on workshop from June 19th-20th, where interventional cardiologists were able to perform new procedures themselves under the professional guidance of Prof. Sievert.

This is the only course of its kind dedicated to catheter treatment of congenital and structural heart disease in children and adults outside of the US.

### June 16th

As a tradition of the CHD workshop, the outcome of last year's patients' was presented in the first lecture given by Madlen Reschke from the CardioVascular Center Frankfurt. The first session on this morning was an update on imaging in congenital heart disease. There were several lectures about TEE, intracardiac echo, CT, MRI and EBT.

Two live interventions (coarctation and hypoplastic left heart syndrome with mitral and aortic atresia) performed by Dr. John Cheatham were transmitted from the Children's Hospital in Columbus, Ohio (USA).

During lunch, step-by-step workshops about ASD closure and intracardiac echo

were held. The first afternoon session was about ASD closure and, as a world premiere, a patient's ASD was closed using the new Solysafe device. The second afternoon session called "Obstructions and Occlusions" treated subjects such as RV and LV outflow obstructions and obstruction of the Vena cava.

Live cases on this day comprised several cases of ASD, PFO and VSD closure, as well as balloon angioplasty for pulmonary stenosis. In one patient, left atrial appendage occlusion and closure of a complex ASD were performed in the same procedure.

Thursday afternoon sessions were followed by an ev3 symposium on PLAATO (*Percutaneous Left Atrial Appendage Transcatheter Occlusion*) and a welcome reception.

### June 17th

Various posters on congenital and structural heart disease were on display the entire day.

Friday morning lectures were about PDA and miscellaneous subjects such as coronary, pulmonary and peripheral fistulae, fetal interventions and hybrid procedures, emphasizing the importance of cooperation between interventional cardiologists and surgeons. Lectures were amended by live case transmissions from Birmingham's Children's Hospital (UK), performed by Dr. Joseph DeGiovanni. They included post Fontan fenestration, right hypoplastic heart syndrome with pulmonary atresia and intact ventricular septum as well as double outlet right ventricle with transposition of the great arteries.

In the lunch symposia, tips and tricks for PFO and PDA occlusion were presented.

In the afternoon, the first session was about left atrial appendage occlusion. After an excellent presentation of left atrial appendage anatomy by Dr. Yen Ho, the newest results of left atrial appendage occlusion with all devices currently available were presented.

A large variety of educational live cases was transmitted, concerning closure of ASD, PFO, VSD, paravalvular leaks, stenting of coarctation and catheter ablation for HOCM.

Patent foramen ovale was the subject of the second session held on Friday afternoon. After two didactic lectures about PFO basics and an update on migraine, divers and other indications, an update of the MIST (*Migraine Intervention with STARFlex Technology*) trial results was presented. Afterwards, the session focused on the newest devices and methods for PFO closure, such as the Velocimed

Premere device, the bio-degradable BioSTAR device and, as a world premiere, the new Cierra device, closing PFOs by radiofrequency only- no occluder is left behind.

After a long day full of state-of-the-art lectures and various live case demonstrations, social dinner was held at the Opel factory in Russelsheim. The congress attendees had the opportunity to visit the final production process of Germany's oldest car factory.

### June 18th

Saturday was another busy workshop day, starting with yet another expert presentation of different types of ventricular septal defects in specimen hearts by Dr.



Dr. Horst Sievert, Course Director of Catheter Interventions in Congenital and Structural Heart

Yen Ho. After an overview of the European VSD trial, different devices for VSD closure were presented. The session ended with a discussion on catheter versus surgical closure of post-myocardial infarction VSDs.

As a highlight of the second session on Saturday, the most recent results and experiences of transcatheter valve replacement were presented by leading interventionalists in this field such as Dr. Alain Cribier, Dr. Ziyad Hijazi and Dr. Carlos Ruiz.

The lunchtime symposium was about tips and tricks in transcatheter treatment of coarctation and perimembranous VSD.

A large variety of complex live cases was performed in the catheterization laboratory of the CardioVascular Center Frankfurt on this day: coiling of a pulmonary fistula, left atrial appendage occlusion using PLAATO and Amplatzer occluders, ASD, PFO, catheter ablation of HOCM and, as a emergency intervention, treatment of a false aneurysm of the aorta.

The last session of the CHD workshop was about complications with good and bad outcomes in the catheter laboratory and how to avoid them. As a special guest, the session was started by a Lufthansa pilot and his splendid talk about "How to prevent complications in aviation and beyond," which was very well received by all attendees.

#### June 19th and June 20th

In the unique hands-on workshop after the end of the CHD congress, more than 20 attendees improved their knowledge about ASD and PFO closure in the CardioVascular Center Frankfurt. Under the guidance of Prof. Horst Sievert, world leader in ASD and PFO closure, the participants were able to perform these procedures themselves, using various de-

vices such as the new Velocimed Premere device.

With many live cases, step-by-step procedures and educational lectures, the "Workshop on Catheter Interventions in Congenital and Structural Heart Disease" is the most important interventional meeting on congenital heart disease in Europe, and one of the largest in the world. It stresses the practical abilities and experience of interventional cardiologists.

Next year's CHD congress will be held in Frankfurt, Germany, from June 8-10, 2006. For more detailed information and registration, please visit the CHD website: [www.chd-workshop.org](http://www.chd-workshop.org).

~CCT~



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#### Correction in November 2005 issue

In "Steep Stent's Angle to the Reference Vessel Promotes Neointima" by Masataka Kitano, MD; Satoshi Yazaki, MD, Hideshi Tomita, MD; Koji Kimura MD; Toshikatsu Yagihara, MD; and Shigeyuki Echigo, MF, figures 2, 3, 5 and 6 were intermixed. To see the correct figure placements, see the November issue at:

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)

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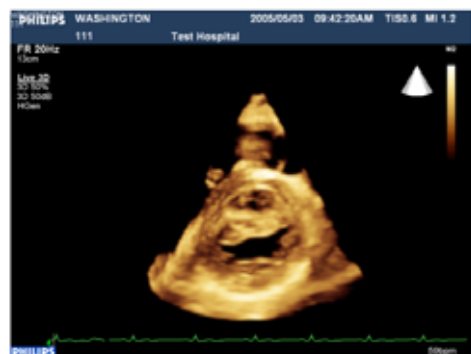
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