

# the Beat

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## Doctor, can I, should I get pregnant?

by Dr Judith Bouchardy

Almost everybody can get pregnant, sometimes with the help of new technology, but will it be safe for me and the baby to come? Will my child have the same problem that I have? Unfortunately, it is not an easy question to answer, and it is not because you had a previous successful pregnancy that the next one will be safe. My intention here is not to give you a crash course on all the risks of pregnancy, but to give you simple advice on what to do first.

First, you need to know if the problem you have is embedded in you, or your loved one's gene pool. If it is, you should seek genetic counselling to have the risk of transmission evaluated. From there, you will have to decide if you want to go ahead with a pregnancy.

Okay, you have decided that the transmission is an acceptable risk. The next step is to see if you and the baby will survive with a good quality of life after and as long as possible.

Of course, since nobody can predict the future, we are stuck with statistics, experiences, and so on. Who knows, you may have a car accident tomorrow or win a million dollars. I have no intention to give you all the statistics or other stuff available, too dry and harsh and it may not apply to you anyway. I only want to ask you one thing: check with your cardiologist **before** you make your decision. The cardiologist will be able to explain the risk for your health, all the pros and cons specific to you, and change your medications if needed, as some are not good for the baby.

Now, you made the decision... and you are pregnant. Congratulations! What next? Again: call your clinic! Because of your heart, your team will want to see you on a regular basis, to make sure that everything is going well for you and the baby, and adjust your medications if needed.

In brief? Very simple: check with your team, even years before you start planning for a family, they are there to help you.

A Newsletter  
written by  
Volunteers for  
the well-being  
of Adults  
with Congenital  
Heart Conditions

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# Non-invasive Procedure Can Mend a Broken Heart

by Nancy Jones-Gartshore, RN, BA

The concept that many serious defects can be effectively treated on an outpatient basis without the need for surgical incisions has revolutionized the approach to many congenital heart defects. Interventional cardiology has undergone tremendous expansion and change over the past twenty years. Pediatric/congenital cardiac catheterizations are now performed more for therapeutic procedures than for diagnostic purposes.

Although interventional cardiac catheterization has replaced surgery as the primary treatment for a number of congenital heart defects, it has also provided an additional and complementary treatment for many residual defects. One recent advance includes the use of stents as a vehicle to implant pulmonary valves in failing surgical right ventricle-to-pulmonary artery conduits.

The Medtronic Melody Transcatheter Pulmonary Valve system is designed to benefit patients who have had pulmonary conduits. A conduit (finger-sized plastic tube containing a valve) is implanted to connect the heart's right ventricle to the blood vessels of the lung. Unfortunately, the valve contained in them progressively becomes inefficient. This causes a big volume of blood to seep back into the right ventricle through the leaking valve. Calcium deposits can also narrow the tube. Ultimately, this leads to the right ventricle becoming overworked, and the patients can become significantly tired. Also, these conduits do not grow with the child. Therefore, a conduit is not a solution for life and children affected by this unfortunately have to face numerous operations in order to avoid over working the heart. Repeat surgery is often required around every 7 to 10 years.

In the pediatric and adult populations, conduits are also used for the treatment of severe aortic valve stenosis. This is a narrowing of the valve between the left-sided ventricle (pumping chamber) and the aorta (the main artery leading to the body). The surgical treatment, which avoids the use of an artificial valve, is called the Ross Procedure. The aortic valve is removed and replaced with the patient's own pulmonary valve. The pulmonary valve is replaced with a valved conduit. However these valves and conduits do not last forever. As noted above, degeneration of the valve and a buildup of calcium in the conduit can become problematic.

Previously, repeat surgery involving the periodic replacement of the conduit was the only choice for patients with significant blockage in the right ventricle or significant pulmonary valve leakage.

Recently, the Medtronic Melody Transcatheter Pulmonary Valve Implant has become a newly available option for our patients. Dr. Philippe Bonhoeffer, at Great Ormond Street Hospital for Children in London, England pioneered this technique in 2000. His 100th patient- an 11-year-old Ross procedure patient-received a pulmonary valve in September 2005. Several countries in Europe including France, Spain and Belgium are performing this procedure. Three hospitals in United States started clinical trials in March 2007.

The first Melody Valve implantation was performed in Canada at The Hospital for Sick Children in Toronto in October 2005. The valve was officially commercially available in Canada on January 10th 2007. Following successes in Toronto, Edmonton and Quebec City, The Montreal Children's Hospital (in collaboration with the MAUDE unit) of the McGill University Health Centre performed the first successful implants in Montreal. In early February 2007, Dr. Adrian Dancea, Dr. Giuseppe Martucci and their team successfully implanted valves in four patients-two adolescents,

a young adult and a sixty-year-old man. A fifth was performed at a later date. It is estimated that a total of ten patients will receive valves in 2007.



Melody Transcatheter Pulmonary Valve: consists of a bovine jugular valve sewn inside a laser-welded platinum-iridium stent.

The valve is mounted inside a stent – an ultra-thin, collapsible platinum mesh cylinder of the type commonly used to prop open weak or narrowed arteries. The stent and valve are collapsed, and then mounted on a tiny deflated balloon at the end of a catheter. The stent on the catheter can then be introduced into a blood vessel. Once the catheter reaches the correct place the balloon is inflated and the stent expands to the required width. The balloon is then deflated, the catheter is withdrawn and the stent remains in place. The valve survives this compression and inflation in fully working form, which is why the procedure is so effective. As this non-invasive technique bypasses the need to open the chest, the patient can leave hospital within 24 hours.

What are the advantages of this procedure? Anyone who has had open-heart surgery will attest to the fact that they would avoid this situation if given the choice. Re-opening of the chest multiple times can increase the likelihood of severe complications. This

procedure also allows for the more timely and frequent repair of the conduit. Like those fitted during open-heart surgery, these valves will not last forever. But the hope is that, if necessary, these patients can receive three or four replacement valves using the catheter method before further invasive surgery is required.

How effective is this procedure? One of our teenage patients, a competitive ski racer, had had previous surgeries at age 3 days and 10 years. He needed another conduit replacement at age fourteen but his parents wanted a non-invasive procedure and were willing to go London. Martin became one of the first MCH patients to receive a pulmonary valve implant. Within a week, Martin was back ski-racing. "I've never felt so good," he said "I finished my course and I'm not tired at the end".

## New guidelines regarding antibiotics to prevent infective Endocarditis

The American Heart Association recently updated its guidelines regarding which patients should take a precautionary antibiotic to prevent infective endocarditis (IE).

### New Recommendations:

1. The AHA recommends that most patients no longer need short-term antibiotics as a preventive measure before their dental treatment.

2. According to the new guidelines, patients who undergo a Gastrointestinal or Genitourinary tract procedure do not need antibiotics to prevent endocarditis.

### What is bacterial endocarditis?

Bacterial endocarditis is an infection of the heart's inner lining (endocardium) or the heart valves. This can damage or even destroy your heart valves. Endocarditis

rarely occurs in people with normal hearts. However, if you have certain preexisting heart conditions, you're at increased risk for endocarditis.

### How does it occur?

Bacterial endocarditis occurs when bacteria in the bloodstream lodge on abnormal heart valves or other damaged heart tissue. Certain bacteria normally live on parts of your body, such as the mouth and upper respiratory system, the intestinal and urinary tracts, and the skin. It is common that some bacteria enters the blood stream during invasive procedures. However, endocarditis is rare.

The guidelines, published in *Circulation: Journal of the American Heart Association (April 2007)*, are based on a growing body of scientific evidence that shows that, for most people, the risks of taking prophylaxis antibiotics for certain procedures outweigh the benefits. Unnecessary use of antibiotics could cause allergic reactions and dangerous antibiotic resistance.

### Patients who still need antibiotic prophylaxis for dental treatments:

- Artificial heart valves
- History of endocarditis
- Specific congenital heart conditions:
  - unrepaired or incompletely repaired cyanotic congenital heart disease, including those with palliative shunts and conduits

### Antibiotic recommendations:

		Regimen: single dose 30 to 60 min before procedure	
Situation	Agent	Adult	Children
Dental	Amoxicillin	2 g	50 mg/kg
Unable to take oral medication	Ampicillin, Cefazolin or Ceftriaxone	2 gm IM or IV 1 gm IM or IV	50 mg/kg IM or IV 50 mg/kg IM or IV
Allergic to Penicillins-oral	Cephalexin, Clindamycin, Azithromycin or Clarithromycine	2 g 600 mg 500 mg	50 mg/kg 20 mg/kg 15 mg/kg
Allergic to Penicillins and unable to take oral medication	Cefazolin, Ceftriaxone or Clindamycin	1 g IM or IV 600 mg IM or IV	50 mg/kg IM or IV 20 mg/kg IM or IV

- a completely repaired congenital heart defect with prosthetic material or device, whether placed by surgery or by catheter interventions, during the first six months after the procedure
- any repaired congenital heart disease with residual defects at the site or adjacent to the site of a prosthetic patch or prosthetic device
- Cardiac transplant which develops a problem in a heart valve.

The new recommendations apply to many dental procedures, including teeth cleaning and extractions. Patients with congenital heart disease can have complex anatomy.

You should check with your cardiologist if there is any question at all as to the category that best fits your needs. The AHA guidelines emphasize that maintaining optimal oral health and practicing daily oral hygiene are more important in reducing the risk of endocarditis than taking preventive antibiotics before a dental visit.

### The following patients do NOT require antibiotic prophylaxis:

- Mitral valve prolapse
- Rheumatic heart disease
- Bicuspid valve disease
- Calcified aortic stenosis
- Congenital heart conditions such as ventricular septal defect, atrial septal defect
- Hypertrophic cardiomyopathy

## Adults with congenital heart disease, a growing community

by Raluca Ionescu-Ilttu, MSc,  
and Nathalie Comtois, RN



The number of adults living with severe congenital heart defects has doubled in the last 15 years, standing proof of the impressive advances in cardiac surgery and pediatric care in the last 50 years.

A recent study coordinated by Dr. Marelli from the MAUDE Unit and published in *Circulation* journal this year has shown for the first time that there was a continuous rise from year 1985 to year 2000 in the prevalence of adults with heart defects. This increase is likely due to both a constant increase in the number of children born in 1960s and 1970s who survived to adulthood and an increase in survival among patients born before 1960s who were already adults in 1985 when the study began.

The increase in the number of children who survive to adulthood is likely to continue as the new generation of children born and operated during the golden era of cardiac surgery –1980s and 1990s – will become adults in the next 20 years. Cardiologists and patients want to make sure that in the next 20 years we also improve the survival and quality of life of this new generation.

Adults with heart defects need to be routinely checked by specialists in congenital heart disease to pick up and treat early any changes in their health status. Two centers specialized in the care of adults with congenital heart disease -MAUDE Unit at McGill University Health Center and a second one at the Montreal Heart Institute- have been set up in Quebec in the last few years. It is important that you, the patients, keep your appointments. Working together - patients, doctors, nurses and other specialists- is the key to make adults with CHD live a longer and healthier life. We are a community.

## CACHnet Annual Meeting

by Shelagh Ross, Vice President and  
Communications Officer, CCHA

CCHA President, John MacEachern had the honour to speak to the members of CACHnet at their annual dinner meeting in Quebec City. He discussed what CCHA had done over the past year, such as securing Life Insurance for its members 40 years and up and Travel, Health and Dental coverage for all members. He mentioned that Manulife Financial was being an incredible corporate citizen as they will be returning some of their premiums to CCHA for CHD research and education.

The famous 'Cardiac Key' which John's predecessor, Patrick Mathieu, had developed, was spoke about by advanced practice nurse Jeanine Harrison. The "Fund a Fellow" campaign was announced, a new CCHA program to raise funds to assist the Toronto Adult Congenital Cardiac Clinic in hiring a Fellow. Our target is \$55,000 per year and we hope to help other clinics in their fundraising efforts.

John tried to impress upon the members of CACHnet how badly we need their assistance in growing our organization, because it is only possible to reach CHD patients across Canada by having them put our brochures in their reporting letters and putting up our posters in their clinics. The association between the professional organization and the patient's group could be classed as a great symbiotic relationship, as we both feed off each other while we are both strengthened by our partnership.

Finally, John spoke of the need for CCHA to have a Medical Advisory Board to give us guidance as to where our energies could be best utilized. It would add a considerable amount of credibility to our organization. Since the meeting, CCHA has already secured several key board members. John thanked CACHnet for giving him the opportunity to speak to a group of

people who have saved so many of our lives, who we will always be indebted to, and assured them they could always count on the support of their patients.

## Congenital Camp "Coeur à Coeur"

by Nathalie Comtois, Nurse Clinician

Saturday, September 8, 2007 we held our second outing in Ste-Agathe for the patients of the MAUDE Unit and their family. As a nurse, it was a great pleasure to meet everyone away from the hospital, to share past experiences, good and bad, and to talk about the future. The setting is wonderful and you can check for yourself online to see at:

<http://maude.mcgill.ca>

Most important, it was a day to enjoy play games and having fun together. I am looking forward to repeating the experience next year.



## Toronto Congenital Cardiac Centre for Adults (TCCCA)

The Toronto Congenital Cardiac Clinic for Adults is preparing for another excellent year. We welcome three physicians who are on fellowship in the congenital program; Dr Najif Nadeem (working with Dr Eric Horlick in the congenital interventional/cath service) and Dr David Tannous and Dr Alex Dadashev who are working in the congenital inpatient/outpatient service. We also have welcomed a new staff cardiologist Dr Rachael Wald to the Adult Congenital program.

Toronto will be the site of the 18th International Symposium on Adult Congenital Heart Disease; June 4-7th 2008 at the four seasons hotel in downtown Toronto. This conference is for professionals working in the area

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**TCCCA (continued)**

of congenital cardiology and with management and research lectures given by a faculty from around the world.

We are also in the final stages of planning the 3rd annual Congenital Cardiac Patient Conference and it will be held at Ryerson University again this year as we were thrilled with the facility last year. It will be held on Saturday, May 10th 2008. The program will be available shortly but may include interesting talks such as; "Transplantation in congenital cardiac patients; is it possible", "Arrhythmias; Treatment and Management for congenital patients", "Pacemakers; who what, where, when and why", "Anxiety and hospital memories; strategies to move forward", "Living well with a congenital heart" and many more topics. Registration will start in February so watch for the website address and the program brochure.

**How you can become a CACH Member**

To become a member of the Canadian Adult Congenital Heart Network you must complete an online form to be considered.

Visit this link for details:  
[www.cachnet.org/mem\\_app.html](http://www.cachnet.org/mem_app.html)