

# the Beat

FALL 2003, VOL. 9, ISSUE 1

## WHAT IS PPS?

BY DR. MICHAEL PATTERSON

Post pericardiotomy syndrome is a troublesome postoperative complication of cardiac surgery. It is most often associated with a prolonged hospitalization in at least 25% of cardiac surgery patients. Recognized since the early days of heart surgery, the syndrome has also been described as: post commissurotomy syndrome, post perfusion/pump syndrome, post myocardial infarction (Dressler's) syndrome and post pacemaker syndrome. PPS has even been described following a stab wound to the chest or after a heart biopsy when the pericardium (sac surrounding the heart) has been "nicked" or punctured. This syndrome seems to be triggered in some way by a break in the pericardial integrity allowing "something" in or out of a normally sealed environment around the heart.

**Post:** following

**Pericardiotomy:** cutting open the delicate sac in which the heart is contained

**Syndrome:** a set of signs (appearances) and/or symptoms (complaints) which occur together

### DIAGNOSES

The diagnoses of PPS is a challenge as it consists of fever, chest pain and lung tissue inflammation, all of which are consequences of heart surgery, related to infection or tissue trauma, chest incisions and anaesthesia or pre-existing congestion from the heart defect.

Syndromes are very common in medicine and surgery. In everyday life we may come across chronic fatigue syndrome and may even devise our own such as "Monday morning syndrome". The latter refers to the school age child with a headache, abdominal pain and tiredness which never

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FALL 2003



A NEWSLETTER

WRITTEN BY

VOLUNTEERS

FOR THE WELL-BEING

OF ADULTS WITH

CONGENITAL

HEART CONDITIONS

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# the Beat

## MEDICAL REVIEW

By Doreen Fofonoff

Many individuals with congenital heart disease use herbal medicines. A recent review of the literature on herbal medications by Dr. Ernst in the Canadian Journal of Cardiology in June 2003 revealed that herbal medications might have serious or potentially serious effects on the heart. These effects include abnormal heart rhythms (arrhythmia), inflammation of arteries (arteritis), chest pain, congestive heart failure, high blood pressure, low blood pressure, heart attack, bleeding problems, overdose of cardiac glycosides (i.e. digoxin), pericarditis (inflammation of the protective sac that surrounds the heart), and even death. Dr. Ernst reports that many of these problems relate to toxic herbal ingredients, contamination (i.e. heavy metals) and adulteration (i.e. adding prescription medication to the herbal medication). The exact mechanism of how herbal medications produce these effects on the heart is not known and more research needs to be done. Dr. Ernst indicates that patients must be educated to understand that herbal medications are not "natural and risk free".

Individuals with congenital heart disease should contact their health care provider to make sure the herbal medication does not have any adverse effects on their heart condition. •

occur on weekend mornings or while on vacation. One may appreciate there may not always be all the features in any one case—perhaps just abdominal pain on a Monday morning always improving as the school bus disappears into the distance. So it is in PPS, there may just be wet lungs and irritability or just shoulder pain.

### SIGNS AND SYMPTOMS

Signs (appearances) and symptoms (complaints) of PPS include: fever, chest pain and lung inflammation. These are the principal problems, but the inflammatory reaction which seems to be the root of PPS may involve the nervous system resulting in irritability and ill defined neurological abnormalities such as disturbed consciousness and hallucinations; the gastrointestinal tract with loose stool and abdominal pain and skin and musculoskeletal system with rash and joint pains.

The syndrome was initially readily recognized following relatively minor procedures such as ASD repair and pacemaker implants where rapid uncomplicated recovery was anticipated. Just when the patient was starting to mobilize and feel better, things "fell apart"; fever, without apparent evidence of infection, chest pain out of all proportion to that normally accompanying breastbone or rib incisions, and cough or lung problems often resulting in decreasing oxygen saturations.

The characteristics of the pain are typically pericardial, which is "referred" to the stomach, shoulders, left arm, back, neck, or either side of the chest as there is no site in the brain's body image for the heart and its covering. The inflammation will often result in increased drainage from chest tubes, if still in place and it is often milky or chylous as the underlying process of PPS seems to have a preference for the lymphatic channels. There may be a build up of fluid around the lungs in the pleural space, or around the heart in the pericardium if the drainage tubes have already been removed.

Most major operations involve a wide incision or even removal of the pericardial sac so any

### *What is PPS? continued from page 1*

fluid generated around the surface of the heart in these cases will seep into the lung spaces or even into the abdomen.

Among the additional problems caused by this inflammatory process are atrial and ventricular arrhythmias, a predisposition to "Staph" infection of the tissue and shock like symptoms in some instances.

### HOW COMMON IS THE SYNDROME?

Between 20 and 40% of patients undergoing heart surgery may experience PPS. However, there are considerable unexplained differences between major centres.

### WHO GETS PPS?

Probably any age group is susceptible to PPS. It was once thought that infants were spared of this syndrome, but this is likely because they cannot describe their shoulder pain and they generally have more serious underlying problems masking the PPS.

### HOW DO WE TEST FOR PPS?

There is no specific test for PPS. White blood cells and platelets may sometimes increase dramatically as can the ESR, a non-specific marker for inflammation. Chest x-ray changes of fluid around or in the lungs, often mimicking congestive heart failure, are considered by many as one of the earliest and most sensitive laboratory tests, and if there is any fluid build up around the heart it will produce an enlarging heart shadow on the x-ray or be detected by cardiac ultrasound (echo).

Returning to our other example of a syndrome, where abdominal pain is often a prominent complaint, we must always try and exclude causes such as appendicitis before settling for Monday morning syndrome and treat accordingly.

### HOW DO WE TREAT PPS?

The effects of PPS, such as excessive fluid around the heart, in or around the lungs, are treated sometimes urgently by drainage or cautious diuretic administration; oxygen and even reinstatement of ventilation (breathing machine) may be required.

## VOLUNTEER WORK

Spending your time helping others can be very rewarding. We need you!

We're looking for people to help with advocacy to provincial governments and hospitals to improve the services available to adult patients with congenital heart defects across Canada.

We're looking for people to join our mentorship program - patients supporting patients - friendship, and encourage patients who would welcome a friendly voice, and perhaps speak with someone who has gone through a similar challenge around the time of surgery or special procedures.

Becoming involved in the educational evenings for patients and families would also be greatly appreciated.

We're looking for people to help organize and work on our fundraising program, to offer names of potential donors, and celebrities that may be willing to participate in a fundraising event.

We need people to contribute articles or reviews for upcoming issues of "The Beat".

If you feel you can help in any other way we gladly encourage your participation. Go to [cachnet.org](http://cachnet.org) and click on "how you can help". •

*What is PPS? continued from page 2*

Treating the underlying inflammation is usually done with aspirin, non-steroidal anti-inflammatory drugs or steroids (prednisone).

### HOW LONG DOES IT LAST?

PPS usually lasts for just a few days but can occur for up to three to four months, often with fluctuations in severity. In rare cases, PPS grumbles on for years after the surgery, and occasionally scarring will result in constriction of the pericardial sac, which interferes with heart relaxation and therefore physical performance.

### CONCLUSION

PPS can be thought of as an over reaction of the body to an as yet unidentified stimulant following a breach in the protective membrane around the heart. As in many immune or allergic illnesses the course may be mild or stormy and unpredictable. It should be considered whenever otherwise unexplainable complications including fever, chest pain and lung inflammation occur following heart surgery. •

## TRANSITION TO ADULT CARE: A TEAM APPROACH

BY DOREEN FOFONOFF & BILL HRYHOR

Many children with congenital heart disease (CHD) are now living well into adulthood as a result of improvements in diagnosis and treatment. Eventually, the young adult will have to move from the pediatric to the adult health care system. Youth and their parents have often been reluctant to move to the adult system because it would mean giving up the all that is familiar to them in the pediatric setting. Even pediatric health care providers have been reluctant to "let go" of these young adults. As well, adult health-care providers have not always been ready or, in many instances, willing to take on these patients because of a lack of knowledge of CHD. However, remaining in the pediatric setting may prevent these young adults from becoming responsible for their health care as well as deprive them of appropriate care by those familiar with adult medical issues.

Transition (meaning change) to adult care should be a process and not an event. It should involve the youth, family and health care providers. It must be planned and take into account not only age but also level of maturity and type and severity of the congenital heart condition. Transitioning to adult health care can be a frightening and sometimes overwhelming process for youth and their parents. In the past, transition often

occurred during a crisis, when the young adult was forced by their age or life plans to move to another facility. Today, many centres now have a formal approach to transition the young adult to the adult setting.

The Pacific Adult Congenital Heart (PACH) Clinic at St. Paul's Hospital and the Cardiac program at British Columbia's Children's Hospital (BCCH) in Vancouver identified a need for a formal approach to transition youth and their parents to the adult setting. With support from the Youth Health Program at BC Children's Hospital, a multi-disciplinary cardiac transition team was formed. The team members came from both the pediatric and adult clinics and worked closely together. A variety of educational tools, information exchanges and eventually a Transition Clinic evolved from these meetings.

Early on several problems were identified, including the need for more youth education about their CHD, a general reluctance towards the transfer of care and a need to promote independence. Strategies to enhance the youth's understanding of their health condition and promote independent behaviours and self-advocacy have been incorporated as a regular component of outpatient visits at BC Children's Hospital. Transition

HOW YOU  
CAN HELP

Make a difference, make a donation. The CACH Network and the Adult Congenital Heart Council are a group of lay and professional volunteers determined to promote the interests of Canadians born with heart defects. We need your help to accomplish our objectives.

Thousands of Canadians are now alive and well thanks to dramatic advances in the care of heart defects. Donations are needed to ensure that people with heart defects continue to enjoy a complete life, and to make sure that our children and adolescents will be even healthier as they grow to adult life.

The CACH Network  
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Mississauga, Ontario,  
Canada.  
L5N 2X4

Please make your cheque out to: The CACH Network. All donations are tax deductible and a receipt will be issued for tax purposes. •

*Transition...continued from page 3*

issues are now discussed starting at an early age and reinforced on subsequent visits. Youth ready for transition to the adult setting are identified by the pediatric team and they and their parents are invited to attend a 3 hour Transition Clinic at St. Paul's Hospital. The Clinic is held twice a year. A team of adult and pediatric health care providers (physicians, nurses, psychologist, and social worker) and PACH Clinic patients participate in the session. The clinic includes an overview of the adult congenital heart clinic, what is different between pediatric and adult care, the transition process, a tour of the adult clinic and diagnostic areas and

two break-out sessions. The session for parents focuses on how to relinquish their role as the primary care provider and how to foster their youth's independence. The youth session focuses on promoting self-advocacy and health care issues relevant to youth (i.e. body image, choosing careers). The pediatric team also provides the youth with health passports and wallet cards detailing their congenital heart condition.

Evaluations of this clinic, including feedback from the youth, their parent and the health care professionals, have been very positive. Involvement in the transition process has highlighted the need for multidisciplinary support for this complex, unique and growing population. •

## PANIC ATTACKS

DR. DANA THORDARSON

A panic attack is a sudden surge of intense fear, accompanied by symptoms such as feeling your heart racing, feeling like you are having trouble breathing, chest pain, feeling dizzy, sick to your stomach, sweaty, trembling, tingling, unreal, out of control, and feeling afraid that you might go crazy, pass out, or die. Panic attacks can happen totally out of the blue, or they may happen in situations where you tend to feel anxious (e.g. on a crowded bus, or before having to give a speech, or while worrying about problems).

A panic attack is just a sudden activation of a normal fear response (the "fight or flight" response). If you were crossing the street and looked up to see a car speeding towards you, your nervous system would respond in ways that help you to run away: your pulse quickens, your blood pressure increases, and you start breathing faster. In a panic attack, the fear response is being set off but there isn't any danger to run away from. If you start feeling your heart pounding for no apparent reason, you might become frightened by this, then you would have more anxiety symptoms, then you would really be afraid something was seriously wrong . . . This vicious circle of anxiety symptoms and responses creates the panic attack.

Although panic attacks can be frightening, they are not dangerous, and they are actually quite common. Over the course of a year, up to 10% of people have at least one panic attack.

Unfortunately, panic attack symptoms are quite similar to symptoms of some heart problems. For most people with panic attacks, their doctor reassures them that their hearts are healthy, and they are having symptoms of anxiety and panic. However, if you have heart problems, it can be difficult for your doctor to determine whether the symptoms are related to your heart or to anxiety. For some people, their heart symptoms trigger a panic attack, and they experience a mixture of heart and anxiety symptoms. For example, you might have palpitations due to occasional episodes of an abnormal heart rhythm. If your first thought is, "Oh No! My heart is going to stop beating!" this will set off an additional anxiety response, leading to even more symptoms, leading to even more catastrophic thoughts ("I'm going to pass out and die right here!"), and so on – the vicious circle of a panic attack. If instead, you are able to reassure yourself ("Oh, I've had these palpitations before, the doctor said I should just sit down until they go away"), you will experience fewer symptoms and the whole episode might be over sooner.

## BOOK CONTEST

It's that time again...we're giving away two copies of the book "Congenital Heart Defects - Decision Making for Surgery" written by Antonio F. Corno. Expressly created to assist with decision making for surgical treatment of congenital heart defects, this new reference covers all relevant aspects. The only way to win is to log-on to [cachnet.org](http://cachnet.org)!

## THE BEAT DISCLAIMER

The material in this publication is provided as a matter of interest. It should not be used as a substitute for professional assistance and does not necessarily reflect the views of the organization or its members.

### *Panic...continued from page 4*

There are several ways to treat panic attacks. Many people are able to cope with occasional panic attacks, even those that are set off by real heart symptoms, by reminding themselves that they have had these symptoms before, and if they can relax and focus

on taking slow deep breaths, they will soon go away. If you have frequent panic attacks, anti-depressant or anti-anxiety medications are often helpful in preventing them by reducing the anxiety response. Cognitive-behaviour therapy for panic is also effective but if you live outside a large city finding a therapist with experience in this area can be difficult. •

## CLINIC UPDATES

### TORONTO CONGENITAL CARDIAC CENTRE FOR ADULTS (TCCCA)

Lots of happenings in TO these days - Toronto has had the pleasure of educating physicians sent from around the world to work within our clinic. These men and women come to the TCCCA with a desire to do intense training in congenital cardiology and then return to their respective countries to care for congenital patients there. Recently, we have had Fellowship Cardiologists from England, Switzerland, Sweden, Singapore, Thailand and of course Canada. These people have been a wonderful asset to our team here in TO.

We are getting our education sessions back up and running now that SARS is officially over and we can meet in groups again. The Transition program is continuing its joint program development with Hospital for Sick Children's. We held a session to welcome 42 patients and families to the adult health care environment on August 21. We will continue to have these sessions twice a year and will notify all new patients by mail of the upcoming dates. The next one is scheduled for February/March.

Since the beginning of the education nights done here in TO we have covered topics such as Tetralogy of Fallot, TGA and the Mustard procedure and Fontan procedure. In the session we discussed with patients; the anatomy and physiology, medical management, what to expect down the road and research being done. These nights are very interactive and informative. We videotaped these sessions and they are available through our clinic. There will be another patient education night in October. The actual topic and date is to be set soon.

The Toronto congenital clinic is running a campaign to support programs and education for its patients and staff. We are pleased and touched that so many people who have been helped by our clinic have supported the TCCCA. - *Jeanine Allen*

### CALGARY ADULT CONGENITAL HEART CLINIC

The "Golf for Marfan" Marfan Syndrome 2nd Annual Charity Golf Tournament is being held on Sept. 27 at the Nursery Golf and Country Club in Lacombe. This is a great fun filled event.

The Canadian Down Syndrome Society is presenting Adults with Down Syndrome: Understanding their complex health needs on November 4th and 5th in Calgary. This event is for health professionals and families. For more information or to register call 403-289-4326 or email [kennedee@shaw.ca](mailto:kennedee@shaw.ca) - *Lori Newman*

### PACIFIC ADULT CONGENITAL HEART CLINIC (PACH)

A research project examining the quality of life and burden of disease for adults with congenital heart disorders and arrhythmias (irregular heart rhythms) will soon be underway in our clinic. The researchers are looking at the quality of life of two groups of patients, Fontan repairs and Mustard repairs and those who have arrhythmias and those that do not.

Health care professionals and patients from the PACH Clinic in Vancouver are participating in a panel session at a collaborative conference for families and professionals by families and professionals sponsored by The Children's

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and Women's Education and Research Centre at BC Children's Hospital entitled "Building Bridges, Sharing the expertise. Panel members include patients, Jo-Ann Fong, Grant Hawkins, Angelo Ma and Reena Janmohamed as well care providers, Doreen Fofonoff Clinical Nurse Specialist, Dr. Michael Patterson pediatric cardiologist, and Dr. Quincy Young, psychologist. The session is

# SURFING THE INTERNET

BY DOREEN FOFONOFF

Do you surf the Internet? A number of individuals with congenital heart conditions often search the Web for health related information. The number of Web sites offering health information has grown by leaps and bounds over the past several years. However, it can often be difficult to tell whether or not the information you find is reliable and accurate.

Anyone can publish on the Internet and much of the health information is not regulated. Many web sites offer high quality information but others may have inaccurate or misleading information. You should evaluate the quality of the information you find and not take it at face value. Much of the information may be of a general nature and does not constitute medical advice. The Internet can supplement (but never replace) advice from your doctor or qualified health professional. You should always consult them regarding information you found on the Internet, as your own personal situation may be different.

Here are some questions to keep in mind as you surf the Internet:

**Who runs the Web site?**

Any web site should make it easy for you to learn who is responsible for the site and its information. Medically trained and qualified health professionals should give any medical or health advice. Make sure the source is credible. Look for sites of trustworthy organizations with a good reputation.

aimed at youth attending the conference and focuses on "Asking The Tough Questions" about transitioning to the adult health care system.

The next Transition Clinic for youth and their families will be held on November 5, 2003 at St. Paul's Hospital from 5:30 PM to 8:30 PM. Anyone interested in attending should contact Doreen Fofonoff at 604-806-9005 or email [dfofonoff@providencehealth.bc.ca](mailto:dfofonoff@providencehealth.bc.ca) - **Doreen Fofonoff** •

**Who pays for the Web site?**

The source of the web site's funding should be clearly stated or readily apparent. For example, addresses ending in .com are commercial businesses, .edu indicates an educational institution, .gov are government sponsored sites, .net refers to an Internet organization or provider, and .org are non profit organizations and groups.

**Where does the information come from?**

Is the site a Canadian site? Health information on non-Canadian sites can be different to that provided on Canadian sites, e.g. different health care systems, medications, etc. If the Web master of the site did not develop the information, the original source should be documented. Compare data from different sites to make sure that there is a consensus of opinion.

**How current is the information on the site?**

Is the information out of date? Information on the web sites should be reviewed and updated regularly. The last review date should be clearly posted.

**Remember to always consult your physician or other health care provider before acting on any health information you review on the Internet.**

To read the full article and the resources for this article, visit our website: [cachnet.org](http://cachnet.org) •

