22nd International Symposium on
Adult Congenital Heart Disease

“BEYOND SAVING LIVES”
Toronto, Ontario, Canada
May 30 - June 2, 2012
Course Information

This Symposium, organized in partnership with the Oregon Health & Science University in Portland (Oregon), Cincinnati Children’s Hospital Medical Centre, University of Cincinnati (OHIO) and the University of Toronto, is a unique forum where medical professionals can meet their colleagues from around the world and exchange ideas and information in the field of Adult Congenital Heart Disease.

International faculty and attendees have gathered annually to educate, learn and receive updates about the latest innovations in the diagnosis and management of Adult Congenital Heart Disease. This Symposium features a highly dedicated academic international faculty team.

‘Beyond Saving Lives’ is the theme of the Symposium. Thousands of lives of children have been saved, but we are facing new challenges in the growing and aging congenital heart disease population. In addition to the common long-term complications such as heart failure, arrhythmias, the Fontan disease, pulmonary arterial hypertension and others, we are challenged with end of life questions and the provision of supportive care, subjects which have been ignored and neglected in our young patients.

Dr. Ivan Rebeyka, Edmonton, will be the distinguished speaker of the Dr. William G. Williams Lecture. Dr. Gary Webb, Cincinnati, was the inaugural speaker of this lecture, which was introduced in honor of the Dr. Williams’ contribution to the field of congenital heart disease in 2008. Dr. Ivan Rebeyka will be the distinguished speaker at this year’s meeting; the title of his presentation is Hypoplastic Left Heart Syndrome – New Challenges of a New Generation of CHD Patients.

We expect the Symposium to provide the best of science and education in this area of practice. The Program is designed for all healthcare professionals working with Adult Congenital Heart Disease (ACHD) and should familiarize participants with the latest clinical information on the diagnosis and management of ACHD. Nursing and Congenital Cardiac Care Associates will have a major organizational and educational role within this Program.

Learning Objectives:

At the end of this program the participant will be able to:

1) To describe the long-term complications and outcomes in adults with congenital heart disease;
2) To recognize congenital heart disease as a chronic disease from childhood into adulthood
3) To estimate the importance of a systematic, multidisciplinary team approach to provide excellent care for adults with congenital heart disease;
4) To recognize the need to participate in a network of centers with expertise in congenital heart disease;
5) To integrate the important role of advanced nurses/nurse practitioners/cardiac care associates in providing comprehensive care for adults with congenital heart disease;
6) To appraise the ignored challenge of end of life/supportive care and to employ the concept of advanced care;
7) To formulate a rational approach to the diagnosis and treatment of adults with congenital heart disease;
8) To integrate modern treatment strategies for arrhythmias into your practice;
9) To assess the risks for pregnancy in women with congenital heart disease;
10) To recognize the needs to improve patient care, education and research globally.

Erwin Oechslin
Chair, Course Director

Accreditation Statement

“This event is an accredited group learning activity under Section 1 as defined by the Royal College of Physicians & Surgeons of Canada for the Maintenance of Certification program. Approved by the Canadian Cardiovascular Society for a maximum of 27 credits.”

This program has been reviewed and approved by the:

Canadian Cardiovascular Society  Société canadienne de cardiologie

An application for contact hours has been submitted to the Pennsylvania State Nurses Association
Disclosure Statement

The following faculty members have indicated that they have a financial interest, arrangement, or affiliation with one or more commercial organizations that could be perceived as a real or apparent conflict of interest in the context or the subject of their presentation(s). The existence of potential conflicts of interest does not necessarily indicate a bias. However it is our ethical obligation to inform organizers and participants so that they are made aware of any relationship that might cause unintentional bias. These faculty members have confirmed that their presentation(s) will be balanced and free of commercial bias and that their affiliation with the organization(s) listed below will not be pertinent, in any way, to the lectures that they will be presenting at the 22nd International Symposium on Adult Congenital Heart Disease, “Beyond Saving Lives” 2012.

<table>
<thead>
<tr>
<th>Name of Faculty Member</th>
<th>Affiliation/Financial Interest</th>
<th>Name of Organization(s)</th>
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Presenters are required to display a slide and to disclose any conflict(s) of interest at the time of the presentation(s). If a faculty member is not contained in the list above, then she/he has no real or apparent conflict(s) of interest to disclose.
7:00 am – 5:00 pm           Registration – GRAND BALLROOM FOYER
7:00 am – 7:45 am           Full Breakfast – GRAND BALLROOM FOYER
8:00 am – 5:45 pm           Posters on Display – GRAND BALLROOM FOYER

7:45 am – 8:00 am – GRAND BALLROOM
Welcome – Opening Comments
Peter Liu, Toronto
Erwin Oechslin, Toronto

8:00 am to 10:00 am – GRAND BALLROOM
Setting the Stage – The Top 10 Challenges After Saving Lives For ……
Chairperson: David Sahn, Portland & Jack Colman, Toronto

- ACHD Cardiologists
  Gary Webb, Cincinnati
- Congenital Surgeons
  Glen Van Arsdell, Toronto
- Nurses And Congenital Cardiac Care Associates
  Philip Moons, Leuven
- The Past-President of the International Society of Adult Congenital Heart Disease (ISACHD)
  Barbara Mulder, Amsterdam
- The President of the Canadian Congenital Heart Alliance (CCHA)
  Shelagh Ross, Oakville

10:00 am – 10:30 am (Break) – GRAND BALLROOM FOYER

10:30 am – 12:30 pm – GRAND BALLROOM
Beyond Saving Lives or “Code Palliative”: Providing a Quality Death and Dying Experience
Chairpersons: Gary Webb, Cincinnati & Adrienne Kovacs, Toronto

- Shifting Mortality: What Can We Expect?
  Matthias Greutmann, Zurich
- Advanced Care Planning: Do We Meet Patient Needs and Current Guidelines?
  Daniel Tobler, Basel
- What Can We Learn From Advanced Heart Failure?
  Heather Ross, Toronto
- Conflict At End Of Life: What Does Bioethics Have To Offer?
  Linda Wright, Toronto
- Beyond DNR
  James Downar, Toronto

12:30 pm – 1:45 pm (Lunch) – GRAND BALLROOM FOYER

1:45 pm – 3:15 pm (Simultaneous Break Out Sessions)
Session II To IV Will Be Repeated On Thursday May 31st, 10:30 am – 12:00 pm

Session I: Nursing Session
YORK ROOM A & B
ACHD 101: Anatomy, Physiology And Terminology
Of Common Congenital Heart Disease
Moderator: Laura-Lee Walter, Hamilton
Speaker: Marion McRae, Toronto

Session II-A: Workshop
TRINITY SALON IV & V
Advance Care Planning In ACHD: Practical Information
Moderator: Jack Colman, Toronto
-What Are Examples Of Quality Death And Dying? - Quynu Li, Toronto
-How Do We Involve Palliative Care In The Management Of Our Patients?
  James Downar, Toronto
-How Can We Communicate Effectively About Advance Care Planning?
  Lawrence Librach, Toronto
1:45 pm – 3:15 pm (Simultaneous Break Out Sessions) (continued)

**Session III-A: Case Presentations:**
Toronto CACH Network Team
TRINITY SALON I & II

**Pregnancy & Heart Disease**
Moderator: C. Silversides, Toronto
Panel Members: S. Siu, C. Warnes
B. Mulder, E. Pieper, M. Sermer,
L. Harris, T. Bradley, K. Stout
- Marfan And Dilated Aortic Root
- Mustard With Subaortic Ventricular Dysfunction And Tricuspid Regurgitation
- Eisenmenger Syndrome
- Arrhythmias
- Contraception / In Vitro Fertilization

**Session IV-A: Case Presentations:**
Montreal CACH Network Team
GRAND BALLROOM

**Heart Failure**
Moderator: Heather Ross, Toronto
Panel Members: C. Caldarone,
L. Roche, J. Therrien, A. Redington
P. Khairy, H. Ross
- ccTGA And Severe TR
- Mustard Or ccTGA Patient With A Failing Subaortic RV
- TOF Patient With Severe RV Dysfunction Severe PR And Severe TR +/- LV Dysfunction
- Failing Eisenmenger Patient / Patient With Severe PHT And Heart Failure

3:15 pm – 3:45 pm (Break) – **GRAND BALLROOM FOYER**

3:45 pm – 5:45 pm – **GRAND BALLROOM**

**Pregnancy in ACHD – Beyond The Basics**
Chairperson: Candice Silversides & Jack Colman, Toronto

- How Should We Manage Women Who Have Or Who Develop Ventricular Dysfunction During Pregnancy?
  Carole Warnes, Rochester
- What Is The Best Method of Anticoagulation To Use In Pregnant Women With Mechanical Valves?
  Els Pieper, Groningen
- What Should We Tell Women About Late Effects Of Pregnancy On The Heart?
  Sam Siu, London, Ontario
- What Is The Most Appropriate Peripartum Obstetrical Management Of Women With Congenital Heart Disease?
  Mathew Sermer, Toronto

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**Thursday May 31, 2012**

7:00 am – 7:45 am Full Breakfast – **GRAND BALLROOM FOYER**
8:00 am – 5:45 pm Posters on Display – **GRAND BALLROOM FOYER**

8:00 am – 10:00 am – **GRAND BALLROOM**

**Heart Failure In ACHD – Beyond Drugs**
Chairperson: Judith Therrien, Montreal & Lucy Roche, Toronto

- How To Optimize The Role of Nurses/Congenital Cardiac Care Associates In Heart Failure Management?
  Stephen Crumb, Columbus
- Exercise And Heart Failure: Lessons Learned From The Rehabilitation of Non-CHD Related Heart Failure
  Tanya Holloway, Toronto
- Who Lives and Who Dies – How Do We Assess Risk?
  Luke Burchill, Toronto
- VADs In ACHD – The Good, The Bad, The Ugly?
  Vivek Rao, Toronto
- Transplantation – The Holy Grail: Who, When And Why Not?
  Heather Ross, Toronto

10:00 am – 10:30 am (Break) – **GRAND BALLROOM FOYER**
10:30 am – 12:00 pm (Simultaneous Breakout Sessions)
Sessions (With The Exception Of Session V) Repeated From Wednesday May 30th 1:45 pm – 3:15 pm

Session V: Nursing Session
TRINITY SALON I & II
Why Is The Fontan Circulation So Special?
Moderator, Jeanine Harrison, Toronto
Speaker: Marion McRae, Toronto

Session II-B: Workshop
GRAND BALLROOM
Advanced Care Planning In ACHD: Practical Information
Moderator: Jack Colman, Toronto
- What Are Examples of Quality Death And Dying?
  Quanyu Li, Toronto
- How Do We Involve Palliative Care Services In The Management Of Our Patients
  James Downar, Toronto
- How Can We Communicate Effectively About Advance Care Planning?
  Lawrence Librach, Toronto

Session III-B: Case Presentations
Toronto CACH Network Team
YORK ROOM A & B
Pregnancy & Heart Disease
Moderator: C. Silversides, Toronto
Panel Members: S. Siu, B. Mulder, E. Pieper, M. Sermer, L. Harris, C. Warnes, T. Bradley, C. Laskin, K. Stout
- Marfan And Dilated Aortic Root
- Mustard With Subaortic Ventricular Dysfunction And Tricuspid Regurgitation
- Eisenmenger Syndrome
- Arrhythmias
- Contraception / In Vitro Fertilization

Session IV-B: Case Presentations
Montreal CACH Network Team
TRINITY SALON IV & V
Heart Failure
Moderator: Lucy Roche, Toronto
Panel Members: C. Caldarone, J. Therrien, A. Redington, L. Roche, P. Khairy
- ccTGA And Severe TR
- Mustard Or ccTGA Patient With A Failing Subaortic RV
- TOF Patient With Severe RV Dysfunction Severe PR And Severe TR +/- LV Dysfunction
- Failing Eisenmenger Patient / Patient With Severe PHT And Heart Failure

12:00 pm - 1:15 pm (Lunch) – GRAND BALLROOM FOYER

1:15 pm - 2:45 pm (Simultaneous Breakout Sessions)
Session VII To IX Will Be Repeated On Friday June 1st 10:30 am - 12:00 pm

Session VI: Nursing Session
TRINITY SALON I & II
“Blue” About ACHD? Eisenmenger, Cyanosis and More....
Moderator: Doreen Fofonoff, Vancouver
- Eisenmengers Syndrome
  Disty Pearson, Boston
- Pregnancy Concerns In Cyanotic Congenital Heart Disease
  Disty Pearson, Boston
- Hematological Effects Of Cyanosis And Other Concerns
  When Living With Cyanotic Congenital Heart Disease
  Desiree Fleck, Philadelphia

Session VII-A: Case Presentations: Western CACH Network Centres (Edmonton/Vancouver)
GRAND BALLROOM
The Fontan Disease
Moderator: Gruschen Veldman, Southampton
Panel Members: B. Deal, L. Harris, C. Caldarone I. Rebeyka, E. Renner, J. Grewal, I. Vonder Muhll
- Failing Fontan Patient With Liver Cirrhosis
- Fontan Patient With Recurrent Supraventricular Arrhythmias
- Fontan Patient With PLE
- Fontan Patient In Class 2 And Reduced Systolic Function Of The Subaortic Ventricle
Thursday May 31, 2012
(continued)

1:15 pm - 2:45 pm (Simultaneous Breakout Sessions) (continued)

Session VIII-A: Workshop
TRINITY SALON IV & V
What I Wish I Could Tell My Referring Clinicians
Moderators: Eric Horlick & Bernd Wintersperger, Toronto
- Top Challenges and Advances in CMR
  Lars Grosse-Wortmann, Toronto
- 10 Challenges Of Interventions in 2012
  Eric Horlick, Toronto
- Hardware In The Chest:
  It Benefits My Patients - Mark Osten, Toronto
  The Benefits Of CMR Before And Problems After Interventions
  Lars Grosse-Wortmann, Toronto

Session IX-A: Workshop
YORK ROOM A & B
Bringing Quality To ACHD Care
Moderator: Gary Webb, Cincinnati
- From Policy To Quality: How Do We Get There?
  Ariane Marelli, Montreal
- From Guidelines To Metrics: How Do We Do It?
  Michelle Gurvitz, Boston
- Quality Initiatives: A Broader Perspective
  Curt Daniels, Columbia

2:45 pm – 3:15 pm (Break) – GRAND BALLROOM FOYER

3:15 pm – 3:45pm – GRAND BALLROOM
Original Oral Poster Presentations in ACHD
Chairperson: Lucy Roche, Toronto

Abstract Winner #3
Congenital Heart Disease Patients Have Disproportionately Lower Use of Ventricular Assist Devices Prior to Transplantation: Impact on Organ Allocation
Broberg C, Gelow J, Weiss J, Song H. - Oregon Health and Science University, Portland OR, United States

Abstract Winner #2
Long-term Outcome of Discrete Subaortic Stenosis in Adults: A Multicenter Study
van der Linde D, Takkenberg JJM, Rizopoulos D, Heuvelman HJ, Witsenburg M, Budts W, van Dijk APJ, Bogers AJJC, Yap SC, Oxenius A, Silversides CK, Oechslin EN, Roos-Hesselink JW. – Erasmus MC, Rotterdam, Netherlands, Adult Congenital Heart Disease Program, Peter Munk Cardiac Centre, Toronto General Hospital, University of Toronto, Toronto, ON, Canada and Leuven University College, Belgium and University Nijmegen Medical Centre, Nijmegen, Netherlands

3:45 pm – 5:45 pm – GRAND BALLROOM
International Society of Adult Congenital Heart Disease (ACHD) Session:
ACHD Around The World
Chairpersons: Barbara Mulder, Amsterdam & Curt Daniels, Columbus

- How To Improve ACHD Care Globally?
  - ACHD Is Taking The Lead In ACHD Global Health
    Curt Daniels, Columbus
  - Care For Adult Congenital Heart Disease in Latin America
    Luis Alday, Cordoba

- How To Educate ACHD Providers Globally?
  Gary Webb, Cincinnati

- How To Overcome Problems And Barriers In Research?
  Koichiro Niwa, Tokyo

- How Can Nurses And Congenital Cardiac Care Associates Impact ACHD Care Globally?
  Disty Pearson, Boston

5:45 pm Adjourn

6:30 pm Social Evening – GRAND BALLROOM FOYER
800 am – 10:00 am – GRAND BALLROOM
The Fontan Disease
Chairperson: Rachel Wald, Toronto & Ivan Rebeyka, Edmonton

- The Fontan Circulation – A Systemic Disease?
  Gruschen Veldtman, Southampton
- Why Does The Fontan Circulation Fail?
  Andrew Redington, Toronto
- How Do I Assess Myocardial Function In Univentricular Hearts By Echo?
  Luc Mertens, Toronto
- Should We Convert All RA To PA Fontan patients?
  Barbara Deal, Chicago
- Failing Fontan And Liver Cirrhosis: Heart And Liver Or Only Heart Transplantation?
  Eberhard Renner, Toronto

10:00 am– 10:30 am (Break)  – GRAND BALLROOM FOYER

10:30 am – 12:00 pm (Simultaneous Break Out Sessions)
Sessions (With The Exception Of Session X) Repeated From Thursday May 31st 1:15 pm – 2:45 pm

Session X: Nursing Session
YORK ROOM A & B
Assessing ACHD Patients: How To Get Right Information to Make Right Decision?
Moderator: Yvonne Balon, Vancouver  
- Inpatient Assessment: What Is “Normal”?
  Quuy Li, Toronto
- Patient Care Tools: Promoting Excellence in Out Patient Care
  Laura-Lee Walters, Hamilton
- Over The Telephone Assessment: What Is Happening on The Other End Of The Line?
  Stephen Crumb, Columbus

Session VII-B: Case Presentations:
Western CACH Network Centres (Edmonton/Vancouver)
TRINITY SALON IV & V
The Fontan Disease
Moderator: Gruschen Veldtman, Southampton
Panel Members: B. Deal, L. Harris, S. Balaji  
- Failing Fontan Patient With Liver Cirrhosis
- Fontan Patient With Recurrent Arrhythmias
- Supraventricular Arrhythmias
- Fontan Patient With Recurrent Supraventricular Arrhythmias
- Fontan Patient In Class 2 And Reduced Systolic Function of the Subaortic Ventricle

Session VIII-B: Workshop
GRAND BALLROOM
What I Wish I Could Tell My Referring Clinicians
Moderators: Lee Benson & Bernd Wintersperger, Toronto
- Top Challenges And Advances in CMR
  Lars Grosse-Wortmann, Toronto
- 10 Challenges Of Interventions in 2012
  Lee Benson, Toronto
- Hardware In the Chest:
  It Benefits My Patients - Mark Osten, Toronto
  The Benefits Of CMR Before And Problems After Interventions
  Lars Grosse-Wortmann, Toronto

Session IX-B: Workshop
TRINITY SALON I & II
Bringing Quality To ACHD Care
Moderator: Gary Webb, Cincinnati
- From Policy to Quality: How Do We Get There?
  Ariane Marelli, Montreal
- From Guidelines To Metrics: How Do We Do It?
  Michelle Gurvitz, Boston
- Quality Initiatives: A Broader Perspective
  Curt Daniels, Columbus

12:00 pm – 1:15 pm (Lunch) – GRAND BALLROOM FOYER
1:15 pm – 3:15 pm – GRAND BALLROOM
Applying New Anti-Arrhythmic Strategies To ACHD – Do They Work?
Chairperson: Louise Harris, Toronto & Seshadri Balaji, Portland

- Arrhythmia And Hemodynamics – Chicken Or Egg?
  Louise Harris, Toronto
- Biventricular Pacing And Synchronization Of Univentricular Hearts: Does It Work?
  Seshadri Balaji, Portland
- How Do We Manage VT In Tetralogy of Fallot?
  Krishnakumar Nair, Toronto & Eugene Downar, Toronto
- Who Needs An AICD For Primary Prevention?
  Paul Khairy, Montreal
- Antiarrhythmic Surgery – What Can I Offer?
  Christopher Caldarone, Toronto

3:15 pm – 3:45 pm (Break) – GRAND BALLROOM FOYER

3:45pm – 5:45 pm – GRAND BALLROOM
The Right Ventricle – What I Always Wanted to Know!
Chairperson: David Sahn, Portland & C. Silversides, Toronto

- How Do I Assess RV Function By Echo?
  Luc Mertens, Toronto
- What Does The MRI Add?
  Craig Broberg, Portland
- Do We Replace The Tricuspid Valve Too Late In Patients With ccTGA?
  Carole Warnes, Rochester
- Training The Subpulmonic LV For A Double Switch Or PA Banding As Destination Therapy?
  Do It Right!
  Andrew Redington, Toronto
- When Do I Replace The Pulmonary Valve In A Volume Loaded RV?
  Judith Therrien, Montreal

5:45 pm – 6:00 pm – GRAND BALLROOM

Original Oral Poster Presentation in ACHD
Chairperson: Craig Broberg, Portland

Abstract Winner Physicians: Young Investigator’s Award
Losartan Therapy has Prominent but Highly Variable Effects on Circulating TGF-β in Marfan Patients
7:00 am – 7:45 am Full Breakfast – GRAND BALLROOM FOYER

7:45 am – 9:45 am – GRAND BALLROOM
Pulmonary Arterial Hypertension – Tough Questions
Chairperson: Erwin Oechslin, Toronto & Matthias Greutmann, Zurich

- Epidemiology And Natural History In PAH and ACHD: Do We Know The Story?
  Ariane Marelli, Montreal
- ASD and PAH – To Close Or Not To Close?
  Helmut Baumgartner, Muenster
- Vasodilator Therapy In Eisenmenger Patients: Who, When And What?
  Alexander Opotowsky, Boston
- Transplantation Of Eisenmenger Patients: Who, When And What?
  John Granton, Toronto

9:45 am – 10:15 am (Break) – GRAND BALLROOM FOYER

10:15 am – 11:00 am – GRAND BALLROOM
Dr. William G. Williams Lecture
Chairperson: Glen Van Arsdell, Toronto

- Hypoplastic Left Heart Syndrome – Challenges From A New Generation of Adult CHD Patients
  Ivan Rebeyka, Edmonton

11:00 am – 12:30 pm – GRAND BALLROOM
This I Believe .......
Chairperson: Karen Stout, Seattle & Isabelle Vonder Muhll, Edmonton

- The Fontan Fenestration Should NOT Be Closed To Keep The Access Open For The Electrophysiologist
  Eugene Downar, Toronto
- The Fontan Fenestration Should Be Closed To Prevent Hypoxemia And Emboli
  Lee Benson, Toronto
- All Patients With Bicuspid Valve Aortopathy Should Be On An ARB
  Judith Therrien, Montreal
- ACE/ARB Have A Very Limited Role In Management Of The Univentricular Circulation
  Lucy Roche, Toronto
- Pulmonary Regurgitant Volume Is More Important Than PR Fraction In TOF Patients
  Erwin Oechslin, Toronto
- Pulmonary Regurgitant Fraction Is More Important Than PR Volume In Patients with TOF
  Craig Broberg, Portland
- Protein Losing Enteropathy In Fontan Patients: Does Anything Work?
  Gruschen Veldman, Southampton
- An ASD Should Be Closed Irrespective Of The Patient’s Age
  Helmut Baumgartner, Muenster

12:30 pm Closing Remarks
Craig Broberg, Portland
Gary Webb, Cincinnati
Erwin Oechslin, Toronto
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<td><strong>Course Directors:</strong></td>
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<tr>
<td><strong>Erwin Oechslin, MD FRCP FESC</strong>&lt;br&gt;Associate Professor of Medicine&lt;br&gt;University of Toronto&lt;br&gt;Director&lt;br&gt;Toronto Congenital Cardiac Centre for Adults&lt;br&gt;Peter Munk Cardiac Centre&lt;br&gt;Toronto General Hospital&lt;br&gt;Toronto, Ontario</td>
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<td><strong>Peter Liu, MD PhD</strong>&lt;br&gt;Heart &amp; Stroke/Polo Professor&lt;br&gt;Scientific Director, Institute of Circulatory &amp; Respiratory Health&lt;br&gt;Canadian Institutes of Health Research&lt;br&gt;Peter Munk Cardiac Centre&lt;br&gt;Toronto General Hospital&lt;br&gt;Toronto, Ontario</td>
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<td><strong>Quany Li, MScN CNCC© RN(EC)</strong>&lt;br&gt;University of Toronto Faculty of Nursing&lt;br&gt;Nurse Practitioner – Adult ©&lt;br&gt;Toronto Congenital Cardiac Centre for Adults&lt;br&gt;Peter Munk Cardiac Centre&lt;br&gt;Toronto General Hospital&lt;br&gt;Toronto, Ontario</td>
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