



# **Clinical research in adult vasculitis in Canada**

Calgary – October 9<sup>th</sup>, 2015

# Disclosures

- Consulting and speaker fees
  - Hoffmann-La Roche
  - BMS
- Advisory boards
  - Hoffmann-La Roche
  - GSK
- Educational subventions (CanVasc)
  - Hoffmann-La Roche
  - Terumo BCT
  - Abbott Immunology
  - BMS
  - Pfizer-Amgen
  - Janssen-Cilag
  - Euroimmun





# Learning Outcomes

1. To review some of the ongoing studies on adult vasculitis, in which Canada participates
2. To review CanVasc activities and projects in adult vasculitis

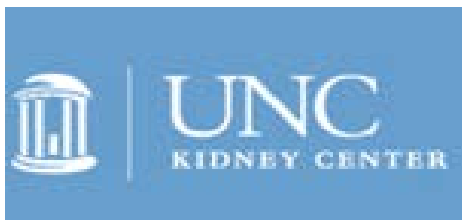






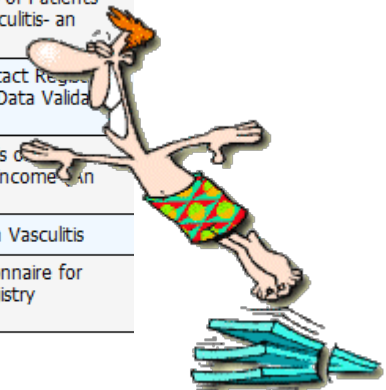
**BRAINWORKS**

The International Inflammatory Brain  
Diseases Study



<b>5503</b> +	10 accruing sites	<b>2</b>	<b>194</b>	<b>2</b>	<b>192</b>
<b>5504</b> +	9 accruing sites	<b>0</b>	<b>101</b>	<b>0</b>	<b>99</b>
<b>5505</b> -	10 accruing sites	<b>12</b>	<b>793</b>	<b>12</b>	<b>785</b>
	Boston University School of Medicine (VCRC)	0	78	0	77
	Cleveland Clinic Foundation (VCRC)	0	130	0	129
	Johns Hopkins University (VCRC)	0	81	0	81
	Mayo Clinic (VCRC)	3	117	3	116
	Mount Sinai Hospital, Toronto (VCRC)	0	155	0	153
	St. Joseph's Healthcare Hamilton (VCRC)	8	125	8	124
	University of Pennsylvania (VCRC)	0	30	0	30
	University of Pittsburgh (VCRC)	0	42	0	40
	University of Utah (VCRC)	0	34	0	34
	VCRC Lab (VCRC)	1	1	1	1
<b>5506</b> -	9 accruing sites	<b>1</b>	<b>218</b>	<b>1</b>	<b>215</b>
	Boston University School of Medicine (VCRC)	0	30	0	28
	Cleveland Clinic Foundation (VCRC)	0	24	0	24
	Johns Hopkins University (VCRC)	0	26	0	26
	Mayo Clinic (VCRC)	0	20	0	20
	Mount Sinai Hospital, Toronto (VCRC)	1	53	1	52
	St. Joseph's Healthcare Hamilton (VCRC)	0	28	0	28
	University of Pennsylvania (VCRC)	0	14	0	14
	University of Pittsburgh (VCRC)	0	10	0	10
	University of Utah (VCRC)	0	13	0	13
<b>5510</b> +	13 accruing sites	<b>5</b>	<b>590</b>	<b>5</b>	<b>584</b>
<b>5515</b> +	5 accruing sites	<b>0</b>	<b>26</b>	<b>0</b>	<b>26</b>
<b>5522</b> +	3 accruing sites	<b>0</b>	<b>20</b>	<b>0</b>	<b>20</b>
<b>5523</b> +	11 accruing sites	<b>0</b>	<b>98</b>	<b>0</b>	<b>83</b>
<b>5526</b> +	7 accruing sites	<b>7</b>	<b>42</b>	<b>6</b>	<b>40</b>
<b>5527</b> +	5 accruing sites	<b>2</b>	<b>8</b>	<b>2</b>	<b>8</b>
<b>5531</b>	Contact Registry Protocol (Online accrual)	<b>0</b>	<b>467</b>	<b>0</b>	<b>467</b>
<b>5533</b>	Contact Registry Protocol (Online accrual)	<b>0</b>	<b>707</b>	<b>0</b>	<b>707</b>

<a href="#">5505</a>	VCRC Longitudinal Protocol for Granulomatosis with Polyangiitis (...)
<a href="#">5506</a>	VCRC Longitudinal Protocol for Eosinophilic granulomatosis with p...
<a href="#">5510</a>	VCRC Genetic Repository One-Time DNA Protocol
<a href="#">5515</a>	VCRC Imaging Protocol for Magnetic Resonance and Positron Emissio...
<a href="#">5522</a>	A Multi-Center, Open-label Pilot Study of Abatacept (CTLA4-Ig) in...
<a href="#">5523</a>	Concurrent Pilot Studies in Giant Cell Arteritis and Takayasu's A...
<a href="#">5526</a>	The Assessment of Prednisone in Remission Trial (TAPIR)
<a href="#">5527</a>	Abatacept (CTLA4-Ig) for the Treatment of Relapsing, Non Severe, ...
<a href="#">5531</a>	Reproductive Health in Men and Women with Vasculitis
<a href="#">5533</a>	Illness Perception, Fatigue, and Function in Systemic Vasculitis ...
<a href="#">5534</a>	Educational Needs of Patients with Systemic Vasculitis- an Intern...
<a href="#">5535</a>	VCRC Patient Contact Registry Patient-Reported Data Validation St...
<a href="#">5536</a>	Impact of Vasculitis on Employment and Income: An online survey o...
<a href="#">5541</a>	PCORI - PROMIS in Vasculitis
<a href="#">5599</a>	Diagnostic Questionnaire for VCRC Contact Registry Participants



# PEXIVAS

a RCT of plasma exchange and  
glucocorticoid dosing in ANCA  
associated vasculitis

On behalf of the PEXIVAS Trial Group



# DCVAS Study

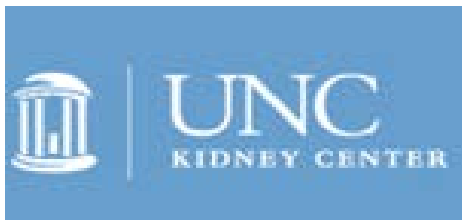
Latest recruitment is over 5032 patients from 129 sites

DCVAS top recruiting sites end June 2015						
	Region	Country	Site	Site Name	Site Investigator	Total Patients
1	EU	SI	JJ	University Medical Centre Ljubljana	Alojzija Hočevar	327
2	EU	GB	NO	Nuffield Orthopaedic Centre Oxford	Joanna Robson	249
3	EU	GB	NU	Nottingham University Hospitals NHS Trust	Peter Lanyon	222
4	NA	CA	ON	St Joseph's Healthcare London, Ontario	Lillian Barra	199
5	EU	DE	TU	Universitätsklinikum Tübingen	Joerg Henes	177
6	OR	RU	MO	First Moscow State Medical University	Sergey Moiseev	155
7	NA	US	BU	Boston University Medical Campus	Peter Grayson	139
8	NA	CA	TO	Mount Sinai Hospital, Toronto	Christian Pagnoux	130
8	EU	DE	JE	Universitätsklinikum Jena	Thomas Neumann	130
8	EU	IT	SS	Santa Maria Nuova Hospital, Reggio Emilia	Carlo Salvarani	130
9	EU	GB	IP	Ipswich Hospital NHS Trust	Richard Watts	118
10	NA	CA	SI	St Joseph's Healthcare Hamilton, Ontario	Nader Khalidi	117
11	EU	CH	UB	University Hospital Basel	Thomas Daikeler	114
12	EU	GB	SE	Southend University Hospital NHS Trust	Bhaskar Dasgupta	113
13	EU	DE	SH	Klinikum Bad Bramstedt	Julia Holle	111
14	EU	CZ	PR	General University Hospital, Prague	Vladimir Tesar	100
15	OR	CN	PU	Peking Union Medical College Hospital, Beijing	Xinping Tian	95
15	EU	IE	VU	St Vincent's University Hospital, Dublin	Eamonn Molloy	95
15	EU	TR	IS	Istanbul University, Istanbul Medical School	Sevil Kamali	95
16	NA	US	CS	Cedars- Sinai Medical Centre, Los Angeles	Michael Weisman	93
17	EU	GB	GR	NHS Grampian, Aberdeen, Scotland	Neil Basu	90
18	EU	TR	HU	Hacettepe University	Ömer Karadağ	85
19	EU	DE	ES	Kreiskliniken Esslingen	Bernhard Hellmich	78
19	NA	US	KU	University of Kansas Medical Centre	Jason Springer	78
20	EU	DE	BE	Immanuel Krankenhaus Berlin	Wolfgang Schmidt	77



**BRAINWORKS**

The International Inflammatory Brain  
Diseases Study



# CanVasc founded in November 2010

## CanVasc Objectives

The CanVasc group was officially created the 1st November 2010, in Toronto.

The proposed CanVasc objectives are to:

1. **organize a dedicated health and research network** with identification of referral (multidisciplinary) centers across Canada for patients with vasculitis. Establishment and regular updates of **Recommendations for the diagnostic and therapeutic management** of patients is part of this objective.
2. **initiate, conduct, and promote studies** (from CanVasc, VCRC or other vasculitis research groups) on vasculitides across Canada (epidemiological, observational, fundamental and, ultimately, therapeutic studies), using an efficient, established and rapidly mobilisable network.
3. **develop educational and awareness programs for health care providers** (training sessions, fellowship, annual meeting...).
4. **stand as the Canadian referral group to identify needs in vasculitis** and consider new drug approvals for vasculitis in Canada (advisory group).





# The CanVasc core members centers





**Executive committee**  
(to be elected every 4 years, as of June 2014)

*President:* Dr. Simon Carrette  
*Vice-president:* Dr. Christian Pagnoux  
*Secretary:* Dr. Nader Khalidi

**Core members**

Province	City	Principal core member (level 1)	Associated core members (level 2)	Affiliated core members / colleagues (level 3)	Contact
<b>Ontario</b>	<b>Toronto</b>	Dr. Simon Carrette; Dr. Rae Yeung (Peds.)	Dr. Christian Pagnoux; Dr. Heather Reich (Nephro.)	Dr. Laurence Rubin; Dr. Ian Witterick (ENT); Dr. Joanne Bargman (Nephro.); Dr. Mary Bell	Division of Rheumatology, Mount Sinai Hospital and University Health Network, The Joseph and Wolf Lebovic Building 60 Murray Street, Ste 2-220 Toronto, Ontario M5T 3L9 Tel. 416-586-4800 Ext. 8549 or 5519 E-mail: VasculitisClinic@mtsina.on.ca
	<b>Hamilton</b>	Dr. Nader Khalidi	Dr. Michael Walsh (Nephro.); Dr. Gerard P. Cox (Respi.); Dr. Parameswaran Nair (Respi.)		Division of Rheumatology St. Joseph's Healthcare Hamilton 25 Charlton Suite 708, Hamilton, Ontario, L8N 4A6 Phone: 905-521-9034 Fax: 905-521-8099
	<b>Ottawa</b>	Dr. Nataliya Milman	Dr. Douglas C. Smith	Dr. Shaun Kilty (ENT); Dr. Brendon McCormick (Nephro.); Dr. Peter Wagner (Nephro.); Dr. Nav Voduc (Respi.); Dr. Shawn Aaron (Respi.); Dr. Kanigsberg (Derm.); Dr. Marco Gomez (Lung Pathol.)	Arthritis Centre at the Ottawa Hospital, Riverside Campus 1967 Riverside Drive, box 37, K1H 7W9, Tel: 613-738-8400, ext. 81871 Fax: 613-738-8228
	<b>Kingston</b>	Dr. Tanveer Towheed	Dr. Marie Clements-Baker; Dr. Michel Melanson (Neurol.)	Dr. Andre Tan (ENT); Dr. David Holland (Nephro.); Dr. Christine D'Arsigny (Respi.)	Department of Medicine Queen's University Room 2066, Etherington Hall, Kingston, Ontario, K7L 3N6 Phone: 613-533-6896




Outlook.com - cpagnoux... x CanVasc homepage x +

www.canvasc.ca vpprn vasculitis

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# The CanVasc website



English - French

Home | About CanVasc | Vasculitides | Ongoing studies | Meetings | Tools for physicians | Links

## Explore CanVasc and its affiliated centers across Canada



CanVasc is the Canadian network for research on vasculitides. It was created in November 2010 by Drs. Pagnoux, Carette and Khalidi. The first task was to identify referral medical centers and physicians across Canada with expertise in vasculitis and who were willing to be part of this new research group (core members). Among its several other aims, important ones are to help conduct studies on vasculitis, provide support and educational material on vasculitides for physicians and other health care professionals and, eventually, optimize the therapeutic management of patients with these rare diseases.

[CLICK HERE](#) for more information on CanVasc.  
[CLICK HERE](#) for more information on national CanVasc meetings

**CanVasc FORUM (and link to CanVasc DropBox) can be [ACCESSED FROM HERE](#)**  
(for CanVasc registered physicians only)

## Review studies on vasculitis actively recruiting in Canada

Several prospective studies on vasculitis are ongoing across the world, including in several Canadian centers. Have a brief overview of these latter ones, including ABROGATE, CLASSIC, PEXIVAS, DCVAS, RITAZAREM and TAPIR on the [study webpage](#) and determine whether any of your patients could participate to any of them.

**PATIENTS can also ENROLL THEMSELVES directly into the VCRC contact registry or the V-PPRN research network!** Several studies are ongoing and rolling already with the active participation of patients leaving in North America, including some studies led by CanVasc researchers! See the links to these registry and network and get more information on this very innovative way to conduct patient-oriented research on the [Link page](#).

## Calgary Vasculitis Symposium - October 8, 2015 - Thursday (07:30-1700)

This symposium is an opportunity to learn about recent discoveries in clinical and translational research and innovations in care for patients with vasculitis aiming to improve the long term outcomes. Free registration [HERE](#).

Topics include Treatment and outcome of ANCA associated vasculitis in 2015, Lung disease in vasculitis, Optimizing care for patients with vasculitis, CNS disease in vasculitis, Clinical research in adult vasculitis, Discoveries in childhood vasculitis, Clinical research in childhood systemic vasculitis, with a keynote presentation (New frontiers in vasculitis research) by Prof. Charles Jennette (University of North Carolina at Chapel Hill, NC, USA).

A research meeting for CanVasc members attending the symposium is planned on the following morning (October 9, 2015).

A Vasculitis Patient and Parent Forum will also be held on Thursday, October 8, 2015, from 6:00pm to 8:00pm in the Auditorium on the 4th floor of the Alberta Children's Hospital for O&A. Patients and families interested can consult the letter of invitation [HERE](#).

1:36 PM  
2015/09/15

Toronto, Ontario M5T 3L9  
Tel. 416-586-4800 Ext. 8549 or 5519  
E-mail: [admin@canvasc.ca](mailto:admin@canvasc.ca) or [vasculitisclinic@mtsinai.on.ca](mailto:vasculitisclinic@mtsinai.on.ca)

## CanVasc core members

Province	City	Principal core members	Associated members
Ontario	<a href="#">Toronto</a>	Dr. Simon Carette; Dr. Rae Yeung (Peds)	Dr. Christian Pagnoux; Dr. Heather Reich
	<a href="#">Hamilton</a>	Dr. Nader Khalidi	Dr. Michael Walsh; Dr. Gerard P. Cox; Dr. Parameswaran Nair; Dr. Sankalp Bhavsar (Burlington)
	<a href="#">Ottawa</a>	Dr. Nataliya Milman	Dr. Douglas C. Smith Dr. Shaun Kilty (ENT); Dr. Brendon McCormick (Neph.); Dr. Peter Magner (Neph.); Dr. Nav Voduc (Respi.); Dr. Shawn Aaron (Respi.)
	<a href="#">Kingston</a>	Dr. Tanveer Towheed	Dr. Michel Melanson (Neuro.); Dr. Marie Clements-Baker
	<a href="#">London</a>	Dr. Lillian Barra	
	<a href="#">Cambridge</a>	Dr. Leilani Famorca	Dr. Brian Hanna
	<a href="#">Newmarket</a>	Dr. Carter Thorne	Dr. Nooshin Samadi
Québec	<a href="#">Sherbrooke</a>	Dr. Patrick Liang	Dr. Ariel Masetto; Dr. Guylaine Arsenault
	<a href="#">Montréal</a>	Dr. Michelle Goulet; Dr. Christian Pineau	Dr. Yves Troyanov; Dr. Evelyne Vinet; Dr. Eric Rich; Dr. Sonia Brachemi
	<a href="#">Québec</a>	Dr. Judith Trudeau; Dr. Paul Fortin	Dr. David Philibert (Neph.)
	<a href="#">Halifax</a>	Dr. Volodko Bakowsky; Dr. Christine Dipchand	Dr. Colm McParland (Resp.)
British Columbia	<a href="#">Vancouver</a>	Dr. Natasha Dehghan; Dr. David Cabral (Peds)	Dr. John Esdaile; Dr. Kim Morishita (Peds); Dr. Kam Shojania; Dr. Barry Kassen; Dr. Pearce Wilcox
Alberta	<a href="#">Edmonton</a>	Dr. Elaine Yacyshyn	Dr. Alison Clifford; Dr. Joanne Homik; Dr. Allan Murray (Neph.)
	<a href="#">Calgary</a>	Dr. Aurore Fifi-Mah Dr. Susan Benseler (Peds)	Dr. Diane Mosher; Dr. Charlene Fell (Resp.)
Manitoba	<a href="#">Winnipeg</a>	Dr. David Robinson	
Saskatchewan	<a href="#">Saskatoon</a>	Dr. Regina Taylor-Gjevre	Dr. Bindu Nair; Dr. Jim Barton (Neph.); Dr. Julian Midgley (Neph. Peds)
Newfoundland	Saint John's	Dr. Majed Khraishi	

Download the updated and complete list of Principal Core, Associated and Affiliated members by clicking [HERE](#)

## CanVasc Regular members

Regular members are defined as physicians other than those listed as core/associated/affiliated members (as listed above), as well as any other

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www.canvasc.ca/vasculitis.htm vpprn vasculitis

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## Selected News and Articles ("CanVasc Journal watch")

*NOTE: Due to copyright policies, we can not directly provide here the full texts of the commented articles. Links will lead you to the Journal pages of the articles, where you will be able to get access to them, through a single article purchase or through your own subscriber account or that of your institution. In case of major, vital and urgent need to get access to one of the articles, you still may try to contact us by email if you have no other options.*

### How the classification of vasculitides can help and impact their therapeutic management

A review and perspective article from some CanVasc core members, in open access, on how the treatment of vasculitides can be decided and guided based upon their classification, how it has changed over the past years and will likely further change in the near future. - June 2015, CPx.

Baldwin C, Carette S, Pagnoux C. Linking classification and therapeutic management of vasculitides. June 2015. Arthritis Research and Therapy. [Link](#)

### Eosinophilic granulomatosis with polyangiitis (Churg–Strauss) (EGPA): Consensus Task Force recommendations for evaluation and management

The EGPA Consensus Task Force experts comprised 23 international experts from different subspecialties from Europe, USA and Canada. Following a modified Delphi questionnaire, they devised 22 recommendations concerning the diagnosis, initial evaluation, treatment and monitoring of EGPA patients. These recommendations will provide physicians with a practical tool for effective and individual management of their EGPA patients. - May 2015 CPx.

Groh M, Pagnoux C, Baldini C, Bel E, Bottero P, Cottin V, Dalhoff K, Dunogué B, Gross W, Holle J, Humbert M, Jayne D, Jennette JC, Lazor R, Mahr A, Merkel PA, Mouthon L, Sinico RA, Specks U, Vaglio A, Wechsler ME, Cordier JF, Guillevin L. Eosinophilic granulomatosis with polyangiitis (Churg–Strauss) (EGPA) Consensus Task Force recommendations for evaluation and management. Eur J Intern Med. 2015 May 9. pii: S0953-6205(15)00144-2. doi: 10.1016/j.ejim.2015.04.022. [Epub ahead of print] [Link](#)

### Results of the Needs Assessment Questionnaire for the development of CanVasc recommendations for ANCA-associated vasculitis

The results of the NAQ are now available at Open J Rheum website: <http://benthamopen.com/FULLTEXT/TORJ-9-16>. This work was the first step towards the development of the CanVasc recommendations for the management of ANCA-associated vasculitis. - April 2015, CPx.

Famorca L, Twilt M, Barra L, Bakowsky V, Benseler S, Cabral D, Carette S, Dhindsa N, Fifi-Mah A, Goulet M, Khalidi N, Khraishi M, McGeoch L, Milman N, Pineau C, Shojania K, Taylor-Gjevre R, Towheed T, Trudeau J, Yacyshyn E, Liang P, Pagnoux C; Canadian Vasculitis network (CanVasc). Development of Canadian Recommendations for the Management of ANCA-Associated Vasculitides: Results of the National Needs Assessment Questionnaire. Open Rheumatol J. 2015 Apr 14;9:16-20. doi: 10.2174/18743129014090100016. eCollection 2015. [Link](#)

### ENT manifestations of EGPA

A general review on ENT manifestations of EGPA by some of the CanVasc core members in open access in the Advances in Cellular and Molecular Otolaryngology: <http://www.cellmoloto.net/index.php/acmo/article/view/27181>. - April 1, 2015. CPx

### Renal Immune Complex Deposition in Patients with Primary ANCA-Associated Vasculitis

AAV is typically described as "pauci-immune" meaning "few immune deposits," and there have been several reports of moderate IC deposition in the renal biopsies of patients with AAV. This descriptive retrospective study from China and published in January 2015 in a rheumatology journal describes the clinical and pathological features and outcomes of 34 patients with ANCA-associated vasculitis (AAV) and immune-complex (IC) deposition on renal biopsy. They compare these patients to 76 other patients with classic "pauci-immune" GN without such intensity of IC deposits. "Pauci-immunity" was defined by the authors as staining of 1+ or less on DIF and the absence of deposits on EM. "IC deposition" was defined as staining of 2+ or more on DIF or deposits on EM. Biopsies were read by two independent renal pathologists.

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www.canvasc.ca/meetings.htm

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## Forthcoming vasculitis meetings (or meetings with vasculitis sessions) and lectures

- **2015 Calgary ACH Vasculitis symposium, Calgary, AL, October 8-9, 2015**  
October 8th is the symposium (open to all health care professionals - website [HERE](#)).
- **2015 ACR scientific conference, San Francisco, USA, November 7-11, 2015**  
General ACR Website <http://www.acrannualmeeting.org>.
- **2017 ANCA Workshop - Prague, CZR OR Tokyo, JPN...**  
More information to come soon...

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## Downloadable vasculitis presentations (PowerPoint/pdf files)

Here are some of the presentations given by CanVasc members during past meetings (for most of them, modified and shortened, in order to respect confidentiality and not to disseminate unpublished results that have been presented orally at the meeting - feel free to contact us for more information).

First (2011) Annual CanVasc meeting

- [The meeting program](#)
- [The French and EUVAS networks](#)
- [The CanVasc network](#)
- [The ongoing and future studies in vasculitides](#) (in which Canadian patients can be enrolled)
- [Updates from the ANCA workshop](#)
- [The CanVasc website](#)

2012 CRA Workshop on Vasculitis (sessions 1 and 2 merged)

- [Challenging vasculitis cases in children and adults](#) - Drs. Benseler and Pagnoux

2012 Canadian Respiratory conference (Vancouver)

- [Brief insight on Churg-Strauss syndrome and CanVasc: the 5 W](#) (C. Pagnoux - shortened)

2012 Ontario Rheumatology Association conference (Muskoka)

- [Vasculitis workshop](#) (L. Famera, C. Pagnoux - shortened version)

GTA Nephrology rounds (Neptune update), Toronto (June 2012)

- [Vasculitis cases](#) (C. Pagnoux - shortened version)

2012 Berlin EULAR/EUVAS update

- [EUVAS](#) (M. Twilt - shortened version)
- [EULAR](#) and new Chapel hill nomenclature (M. Twilt - shortened version)

July 2012, Advisory board, Toronto, ON

- [Update on GPA/MPA and rituximab](#) (C. Pagnoux - shortened version)

August 2012, Health Allied Professional Advisory board, Toronto, ON

- [Vasculitis: an overview](#) (C. Pagnoux - shortened version)

November 2012, Annual CanVasc Meeting - Montreal (SHORTENED versions of some presentations)

Recent Evidence in Vasculitis  
Science and Treatment

REVISIT

Management of AAV in the clinical setting

1:38 PM  
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## For physicians



### Canvasc MD member FORUM

Please note that ONLY medical doctors, registered as CanVasc members (first register to become CanVasc member then create a forum account - access to forum will then be granted). This is a secured and password-restricted forum.



### Vasculitis Clinical Research Consortium (VCRC)

The Vasculitis Clinical Research Consortium is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of vasculitis. The website contains medical information for physicians, health care providers but also patients.



### French Vasculitis Study Group (FVSG)

The FVSG (French Vasculitis Study Group) is a non-profit association created in 1981 by Prof. Loïc Guillevin. The FVSG's goals in the field of systemic vasculitides are to aid and promote research, diffuse updated information to doctors and patients, organize and coordinate therapeutic trials, and compile a register of doctors and investigators working in the field of vasculitis.



### European vasculitis study group

European Vasculitis Study group (EUVAS) is the open collaborative research group of European physicians interested in research and education in vasculitis. The website provides some information on EUVAS activities.



JOHNS HOPKINS  
MEDICINE

### The Johns Hopkin Vasculitis Center WebSite

The purpose of this Website is mainly to provide information about vasculitis for patients, including easy-to-print booklets on each of the main vasculitides, but physicians and research coordinators may also find a lot of useful information and practical tools.



### Cleveland Clinic CME Website - Vasculitis

The Cleveland Clinic Center for Continuing Education has been committed to sharing a wealth of knowledge with physicians, nurses, and other medical professionals across the country and all over the world for more than 75 years. This website contains rich educational material and updates on vasculitis and vasculitis research.

### Rheuminfo RheumInfo.com

RheumInfo.com is a website developed by Dr. Andy Thompson & Marlene Thompson (London, ON) to provide free, honest, accurate, and reliable information for patients and physicians dealing with rheumatic disease. Many simple easy-to-use booklets on treatment, which can be given to help patients manage their treatment on a daily basis, are downloadable.

**Hello CanVasc Forum Administrator**

Show unread posts since last visit.  
Show new replies to your posts.  
There is one member awaiting approval.  
20 October 2014, 20:42:40

News:

[Home](#) [Help](#) [Search](#) [Admin](#) [Moderate](#) [Profile](#) [My Messages](#) [Calendar](#) [Members](#) [Logout](#)

CanVasc Forum

**Forum and CanVasc Information****Unread Posts**

	<b>Forum Information</b> Information about the the forum, its content, rules etc	0 Posts 0 Topics	
	<b>CanVasc Activities and Information</b> Information on CanVasc annual and core member meetings, teleconferences etc	1 Posts 1 Topics	<b>Last post</b> by CanVasc Forum Administrator in 2014 CanVasc annual meet... on 16 June 2014, 15:15:32
	<b>CanVasc Dropbox</b> Link to CanVasc dropbox (including top articles, CanVasc documents for core members etc)	1 Posts 1 Topics	<b>Last post</b> by CanVasc Forum Administrator in DropBox link on 06 February 2013, 21:07:56
	<b>Material for review and guidance for member</b> Miscellaneous material for members to review and/or to help in the administrative tasks	3 Posts 1 Topics	<b>Last post</b> by aviffima in Redcap use for database on 22 May 2014, 23:48:01

**Vasculitis Information****Unread Posts**

	<b>General Discussion on Vasculitis</b>	0 Posts 0 Topics	
	<b>Difficult Cases</b> Discussion about difficult cases (no patient ID allowed)	8 Posts 4 Topics	<b>Last post</b> by Ibarra in Re: Hypocomplementemic U... on 19 July 2014, 18:11:38
	<b>CanVasc Consensus and Recommendations</b> Discussion about the CanVasc recommendations for the management of vasculitis	0 Posts 0 Topics	

[New Posts](#) [No New Posts](#) [Redirect Board](#)[MARK ALL MESSAGES AS READ](#)

# **CIORA grant**

- 1) develop recommendations for LVV***
- 2) implement strategies to disseminate CanVasc recommendations across Canada***
- 3) develop new educational materials, with a systematic web-based process***
- 4) develop strategies to assess the use of the recommendations and educational materials and their impact on practice management of patients***



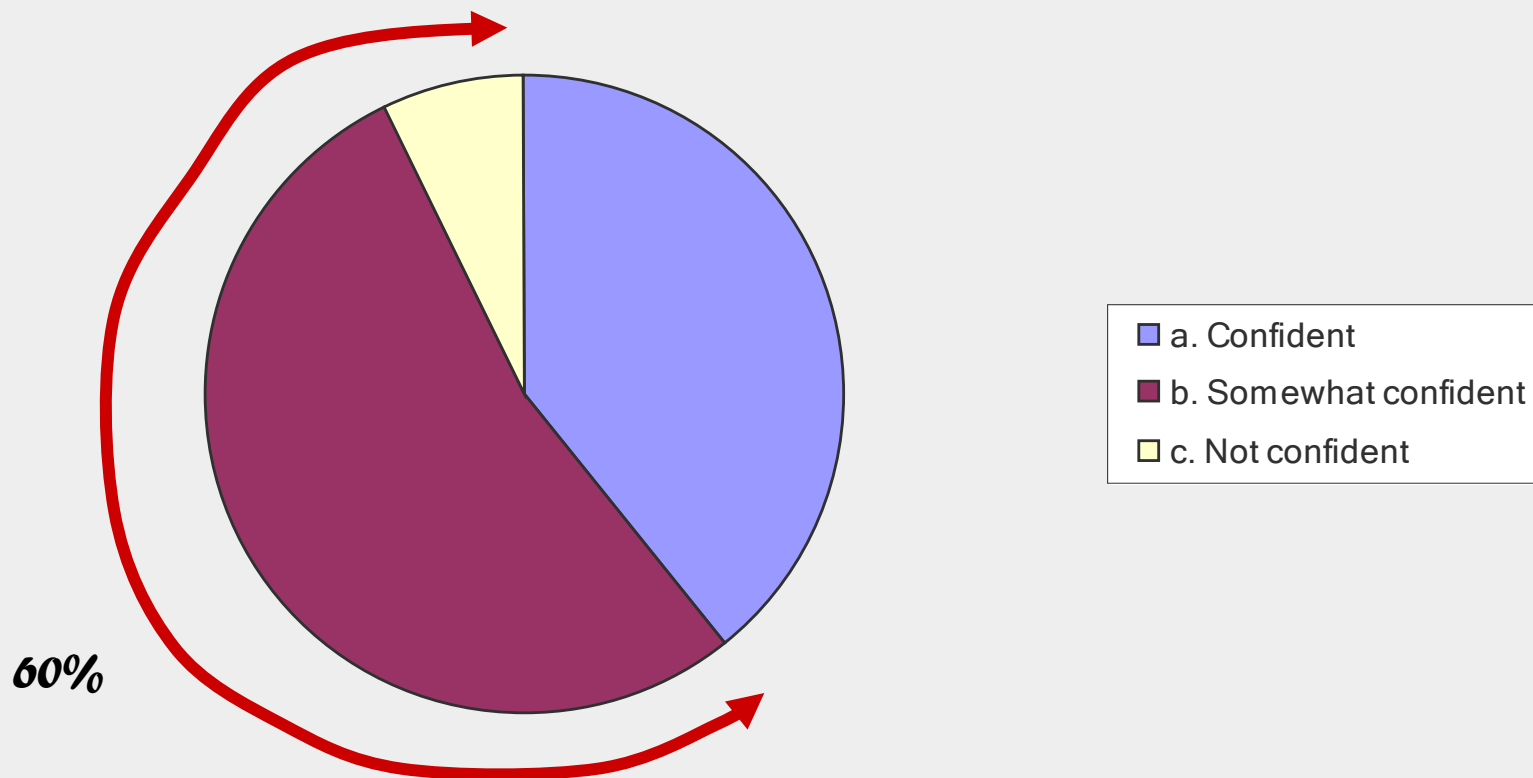
# CanVasc

***recommendations for the  
management of patients with  
ANCA-associated vasculitis***

# Process

- Establishment and regular updates of **recommendations for the diagnostic and therapeutic management** of patients with ANCA-associated vasculitis
- **Needs assessment questionnaire**
  - CRA members
  - CanVasc member list
  - CTS (respirology) + CSN (nephrology)
  - including pediatricians, and some GIM

Overall, how confident do you feel in the management of patients with ANCA-associated vasculitis?



Overall, how confident do you feel in the management of patients with ANCA-associated vasculitis?

Answer Options	Response Percent	Response Count
a. Confident	39.2%	38
b. Somewhat confident	53.6%	52
c. Not confident	7.2%	7
<i>answered question</i>		<b>97</b>
<i>skipped question</i>		<b>24</b>

# Process

→ 37 identified questions

- Review of literature on these questions
  - existing recommendations
  - PubMed + grey literature + proceedings since 2008
- Writing of draft 1 with grading of evidence



<b>Category of Evidence</b>	<b>Evidence Available</b>
1A	From meta-analysis of randomised controlled trials.
1B	From at least 1 randomised controlled trial.
2A	From at least 1 controlled study without randomization.
2B	From at least 1 quasi-experimental study.
3	From descriptive studies, such as comparative studies, correlation studies, or case-control studies.
4	From expert committee reports or opinions and/ or clinical experience of respected authorities.

<b>Strength of Recommendation</b>	<b>Directly based on (level of evidence)</b>
A	Category 1 evidence
B	Category 2 evidence or extrapolated recommendations from category 1 evidence.
C	Category 3 evidence or extrapolated recommendations from category 1 or 2 evidence.
D	Category 4 evidence or extrapolated recommendations from category 2 or 3 evidence.

Dougados M, Betteridge N, Burmester GR, et al. EULAR standardised operating procedures for the elaboration, evaluation, dissemination, and implementation of recommendations endorsed by the EULAR standing committees. Annals of the rheumatic diseases 2004;63(9):1172-6.

# Process

Reviewed by 15 CanVasc core members



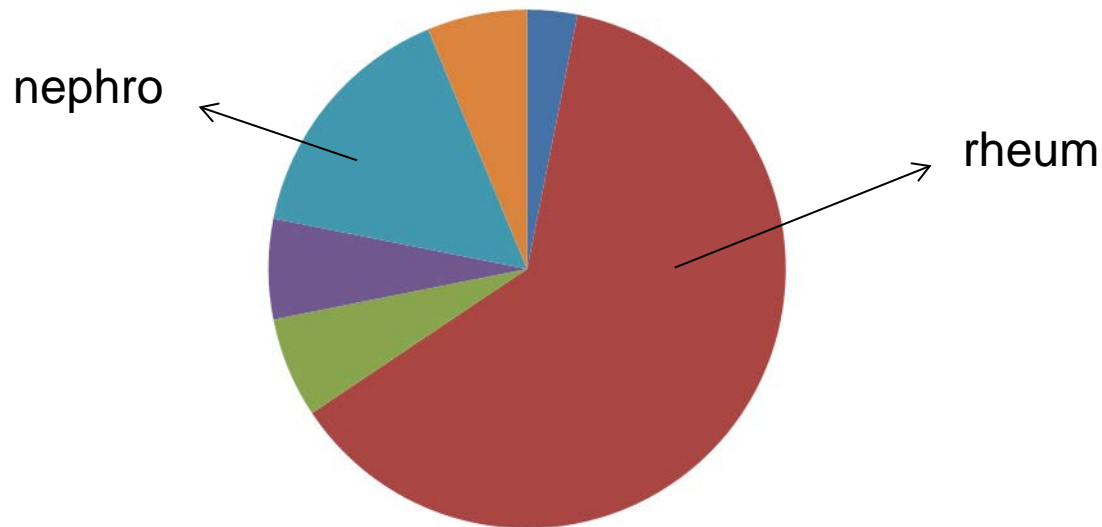
November 2013

# Process

- Revised draft (2) → 07/2014
- Revised draft (2)
  - CanVasc core members  
+ subgroups (CTS, CSN, CRA members)
  - Patient association (VF Canada)
  - Nurses

# Thanks to all the reviewers!

Comments from 33 reviewers (+ VF)



# CanVasc Recommendations for the Management of Antineutrophil Cytoplasm Antibody-associated Vasculitides: Short Version

Lucy McGeoch, Marinka Twilt, Leilani Famorca, Volodko Bakowsky, Lillian Barra, Susan Benseler, David A. Cabral, Simon Carette, Gerald P. Cox, Navjot Dhindsa, Christine S. Dipchand, Aurore Fifi-Mah, Michelle Goulet, Nader Khalidi, Majed M. Khraishi, Patrick Liang, Nataliya Milman, Christian A. Pineau, Heather Reich, Nooshin Samadi, Kam Shojania, Regina Taylor-Gjevre, Tanveer E. Towheed, Judith Trudeau, Michael Walsh, Elaine Yacyshyn, and Christian Pagnoux, for the Canadian Vasculitis Research Network

**ABSTRACT.** *Objective.* The Canadian Vasculitis research network (CanVasc) is composed of physicians from different medical specialties and researchers with expertise in vasculitis. One of its aims is to develop recommendations for the diagnosis and management of antineutrophil cytoplasm antibody (ANCA)-associated vasculitides (AAV) in Canada.

*Methods.* Diagnostic and therapeutic questions were developed based on the results of a national needs assessment survey. A systematic review of existing non-Canadian recommendations and guidelines for the diagnosis and management of AAV and studies of AAV published after the 2009 European League Against Rheumatism/European Vasculitis Society recommendations (publication date: January 2009) until November 2014 was performed in the Medline database, Cochrane library, and main vasculitis conference proceedings. Quality of supporting evidence for each therapeutic recommendation was graded. The full working group as well as additional reviewers, including patients, reviewed the developed therapeutic recommendations and nontherapeutic statements using a modified 2-step Delphi technique and through discussion to reach consensus.

*Results.* Nineteen recommendations and 17 statements addressing general AAV diagnosis and management were developed, as well as appendices for practical use, for rheumatologists, nephrologists, respirologists, general internists, and all other healthcare professionals more occasionally involved in the management of patients with AAV in community and academic practice settings.

*Conclusion.* These recommendations were developed based on a synthesis of existing international guidelines, other published supporting evidence, and expert consensus considering the Canadian healthcare context, with the intention of promoting best practices and improving healthcare delivery for patients with AAV. (J Rheumatol First Release xxxx; doi:10.3899/jrheum.150376)

## *Key Indexing Terms:*

ANCA-ASSOCIATED VASCULITIS      DRUG THERAPY      QUALITY OF HEALTHCARE  
PRACTICE GUIDELINES      CONSENSUS DEVELOPMENT CONFERENCE      VASCULITIS

## **Diagnosis of ANCA-associated vasculitis (AAV)**

- **Statement 1:** The role of ANCA testing
- **Statement 2:** The role of tissue biopsy

## **Classification of Disease Severity**

- **Statement 3:** Severe disease in AAV

## **The Role of Referral Centers for Vasculitis**

- **Statement 4:** Management of AAV patients with Referral Centers for Vasculitis

# Remission Induction of Newly Diagnosed AAV

## Severe, Newly-Diagnosed AAV

**Recommendation 1:** The use of Cyclophosphamide (CYC)

**Recommendation 2:** Rituximab in remission induction

**Recommendation 3:** CYC dose adjustments

**Statement 5:** CYC monitoring

**Recommendation 4:** Duration of remission induction therapy with CYC

**Recommendation 5:** Glucocorticoids in remission induction

**Recommendation 6:** *Pneumocystis jiroveci* prophylaxis

**Recommendation 7:** Plasma exchange in remission induction

## Limited GPA and non-severe EGPA/MPA, Newly-Diagnosed

**Recommendation 8:** Methotrexate in limited GPA

**Recommendation 9:** Therapeutic options in non-severe EGPA and MPA

## **Remission Maintenance**

**Recommendation 10:** Choice of maintenance immunosuppressant

**Recommendation 11:** Rituximab in remission maintenance

**Statement 6:** Maintenance after rituximab-based induction

**Recommendation 12:** Glucocorticoids in maintenance

**Recommendation 13:** Duration of remission maintenance therapy

**Recommendation 14:** Trimethoprim/sulfamethoxazole for maintenance therapy

**Recommendation 15:** The role of topical therapies in localized Ear Nose and Throat (ENT) disease



## **Relapsing Disease**

**Recommendation 16:** Treatment for major severe (life/organ-threatening) relapses

**Recommendation 17:** Plasma exchange in relapsing disease

**Recommendation 18:** Non-severe (non life/organ threatening) disease relapses

## **Refractory Disease and Specific Disease manifestations**

**Recommendation 19:** The role of rituximab in refractory disease

**Statement 7:** The management of subglottic stenosis and retro-orbital tumors

**Statement 8:** The management of refractory/resistant asthma in EGPA

## **Additional and Experimental Therapies**

**Statement 9:** The use of alternate/additional/experimental therapies in refractory AAV

## **Follow-up and Monitoring**

**Statement 10:** Long term follow-up

**Statement 11:** Screening for CYC-induced bladder toxicity

**Statement 12:** Assessment of cardiovascular risk profile in AAV

## **Special patient groups**

**Statement 13:** Planning and managing pregnancy

**Statement 14:** Management of pediatric patients

**Statement 15:** Classification of pediatric patients with AAV

**Statement 16:** Management of pediatric patients with newly diagnosed AAV

**Recommendation 20:** Management of pediatric patients with relapsing or refractory AAV

## Recommendation 2

**We recommend using high dose glucocorticoids with rituximab as 1<sup>st</sup> line remission induction therapy in patients with severe GPA or MPA in whom cyclophosphamide is contraindicated or in whom cyclophosphamide presents an unacceptable risk of infertility.**

Two RCTs have shown RTX (375mg/m<sup>2</sup> x 4 weekly infusions) to be non-inferior to cyclophosphamide at inducing remission in adults with organ or life-threatening disease<sup>40, 50</sup>. In RITUXVAS (n= 44) remission at 6 months was achieved in 91% and 82% of patients treated with cyclophosphamide and rituximab respectively (a non-significant difference). In the Rituximab for ANCA-associated Vasculitis (RAVE) study (n= 197), 64% of the rituximab group patients were in remission off glucocorticoids at 6 months compared to 54% of the cyclophosphamide group (a non-significant difference). In both RCTs, there was no evidence that rituximab is a safer alternative to cyclophosphamide (comparable rate of adverse events in both treatment groups, including infections). For patients in whom cyclophosphamide is not tolerated or there is a valid contraindication to cyclophosphamide, we recommend presenting a case for the funding of rituximab, which is more expensive. We believe that preservation of fertility, when there are no clearly effective methods of doing so, is a valid justification for the use of rituximab in certain individuals, especially patients of child-bearing age. The approved regimen for rituximab in Canada is that used in the RAVE and RITUXVAS trials: 4x weekly infusions of 375mg/m<sup>2</sup>. An alternate regime of 2 x 1g rituximab infusions administered 14 days apart (as used in the treatment of rheumatoid arthritis) may be of comparable efficacy, based on retrospective studies only<sup>51-53</sup>. We therefore recommend using the former regimen when feasible. See *Appendix 4* for rituximab prescribing protocols.

### *Evidence 1B, Strength of recommendation A*

**Barriers to implementation.** In August 2012, The Canadian Drug Expert Committee (CDEC) approved rituximab for the induction of remission in adult patients with severely active GPA or MPA who have a history of severe reaction to cyclophosphamide, in whom cyclophosphamide is contraindicated or who have failed an adequate trial of cyclophosphamide. Rituximab is currently approved according to these criteria in Ontario, British Columbia, Alberta, Saskatchewan, Nova Scotia and Newfoundland (see *Appendix 7*). The drug approval process is underway in the other provinces.

### **Previous Guidance**

#### **2014 BSR<sup>21</sup>**

*All patients with newly diagnosed AAV should be considered as having a potentially severe life- or organ threatening disease and therefore should be assessed for treatment with glucocorticoids (GCs) and pulsed i.v. CYC or RTX.*

*RTX is as effective as CYC for remission induction of previously untreated patients and is preferable when CYC avoidance is desirable (infertility, infection).*

*Both commonly used RTX protocols (375 mg/m<sup>2</sup>/week for 4 weeks; 1000mg repeated after 2 weeks) appear equally effective for induction of remission. The licensed and recommended RTX dosing protocol for the treatment of AAV is 375 mg/m<sup>2</sup>/week for 4 weeks.*

#### **2011 FVSG<sup>20</sup>**

*For first-line treatment, rituximab may be prescribed for the same indications as cyclophosphamide to induce remission of certain GPA and MPA forms. It should preferentially be prescribed to women of childbearing age, especially when they are over 30 years old.*

*Because rituximab was not superior to cyclophosphamide in 2 randomized-controlled clinical trials, the therapeutic choice for a first disease flare is left to the discretion of the treating physician. That decision should be based on the patient's medical history, morbidity factors preexisting AAV, the vasculitis symptoms to be treated and the patient's opinion.*

*The dose of 375mg/m<sup>2</sup>/week x 4 weeks, established to treat lymphoma, was evaluated in the randomized RAVE trial on AAV. Therefore, we recommend that dose with an evidence level of 1.*

#### **Guerry et al., 2011<sup>7</sup>**

*Rituximab is as effective as CYC for remission induction of previously untreated patients. Rituximab may be preferred, especially when CYC avoidance is desirable.*

#### **KDIGO<sup>13</sup>**

*We recommend that rituximab and corticosteroids be used as an alternative initial treatment [of pauci-immune focal and segmental necrotizing GN] in patients without severe disease or in whom cyclophosphamide is contraindicated.*

***Drs. Lucy McGeoch*** (adult rheumatology), ***Marinka Twilt*** (pediatric rheumatology)

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*Drs. Volodko Bakowsky, Lillian Barra, Susan Benseler, David Cabral, Simon Carette, Navjot Dhindsa, **Leilani Famorca**, Aurore Fifi-Mah, Michele Goulet, Nader Khalidi, Majed Khraishi, Patrick Liang, Nataliya Milman, Christian Pineau, Nooshin Samadi, Kam Shojania, Regina Taylor-Gjevre, Tanveer Towheed, Judith Trudeau, Elaine Yacyshyn*

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***VF Canada:*** John Stewart, Katherine Smith, Barbara Tuntoglu (board)

***Sandra Messier***



Get enrolled in a study...



Active GCA	GiACTA (<6 wks CS)
GCA	Gevokizumab
Severe GPA/MPA with lung or kidney	PEXIVAS (<2 wks CS)
Active GPA/MPA (not too severe)	CLASSIC
New GPA/MPA entering remission	BREVAS (<6 wks remission)
GPA at 6-12 remission on CS 6-10mg	TAPIR
Relapsing limited GPA	ABROGATE
Relapsing severe GPA/MPA	RITAZAREM (at relapse)
Refractory/relapsing EGPA	MIRRA
All	Genetic/cytoflux MSH
	VCRC (any time)
	DCVAS (<2 years)

# The CanVasc website



English - French

Home | About CanVasc | Vasculitides | Ongoing studies | Meetings | Tools for physicians | Links

## Summary table of ongoing studies

Severe GPA/MPA with lung or kidney	PEXIVAS (<2 weeks) - <a href="#">website</a>
Not too severe GPA/MPA	<a href="#">CLASSIC</a>
GPA on prednisone for maintenance	<a href="#">TAPIR (website)</a>
Relapsing non-severe GPA	<a href="#">ABROGATE</a>
Relapsing severe GPA/MPA	<a href="#">RITAZAREM</a> (at relapse) - <a href="#">website</a>
All	VCRC cohort (any time)
	VCRC contact <a href="#">registry</a> (any time)
	<a href="#">DCVAS</a> (<2 years)
PACNS	INTERSpace
	<a href="#">BrainWorks</a> (for children; adults soon)

To read more information on each study, click on the name on the study when a link is available and/or read below.

**NOTE (18 June 2015):** inclusions in the BREVAS study (belimumab on top of AZA for maintenance in GPA/MPA) are closed (revised protocol with an achieved target of 100 patients).

**NOTE (14 April 2015):** Inclusions in the GIACITA study (tocilizumab for GCA) are closed in Canada.

**NOTE (5 February 2015):** Inclusions in the MIRRA study (mepolizumab in refractory EGPA) are closed in Canada. The study is still enrolling in US and Europe but should also reach its enrolment targets there soon.

If you still need more detail on these studies or if you think that one of your patients could be eligible for any of this study, do not hesitate to contact us as well ([admin@canvasc.ca](mailto:admin@canvasc.ca)).

## PEXIVAS

PEXIVAS trial is a multicentre, international, phase III, open label randomised controlled therapeutic trial to investigate plasma exchange and glucocorticoid dosing in the treatment of ANCA-associated vasculitis. It is conducted under the aegis of the VCRC, EUVAS and NIH. Several centers in Canada are participating, including centers involved in CanVasc, like Hamilton, where Dr. M. Walsh (associated member of CanVasc), who originally worked on the trial design and is the main investigator for Canada, is established.

The first Canadian patient has been enrolled in late March 2011 in Hamilton, which was the first open center in Canada. All other

# Registries

- Different options, but the same structure and, eventually, items
  - Access
  - RedCap
  - BrainWorks



Outlook.com - cpagnoux...

CanBase | REDCap

https://redcapexternal.research.sickkids.ca/redcap\_v6.7.5/DataEntry/index.php?pid=574&page=adult\_patient\_entry&id=18&event=vprrn vasculitis

msnPubMedutorocanvascGgle NewsRheumatologyGIMDCVASRecruitRDCRNwebCVMDCalcREDCapBrainWorks adBrainWorksScbkCCX-ADJNEJM

Logged in as christian.pagnoux  
Log out

My Projects  
Project Home  
Project Setup  
Project status: Development

Data Collection

Edit instruments

Record Status Dashboard  
View data collection status of all records

Add / Edit Records  
Create new records or edit/view existing ones

Record ID 1  
Select other record

Event: Enrollment (Arm 2: Adult)

Data Collection Instruments:

Adult - Visit Date

Adult - Patient Entry

Adult - Patient Background

Adult - Clinical Features

Adult - Investigations

Adult - Vascular Imaging

Adult - Nonvascular Imaging

Adult - Biopsy

Adult - Physician's Global Assessment

Adult - Treatment

Applications

Calendar

Data Exports, Reports, and Stats

Data Import Tool

Data Comparison Tool

Field Comment Log

File Repository

Help & Information

Help & FAQ

Video Tutorials

Suggest a New Feature

If you are experiencing problems, please contact your REDCap administrator.

CanBase

VIDEO: Basic data entry

Actions: Modify instrumentDownload PDF of instrument(s)

Save Record  
Save and Continue  
Save and go to Next Form

Re-assign this record to another Data Access Group? CanVasc

Editing existing Record ID 1

Event Name: Enrollment (Arm 2: Adult)

Record ID 1

Does the patient meet 1990 ACR and/or Chapel Hill Criteria?  
Yes No

Has the patient consented to study?  
Yes No

Is the patient older than 18 years of age?  
Yes No

Year of birth  
1998

Gender  
Male Female

Date of first symptoms attributable to vasculitis (other than asthma in EGPA)  
15-10-2014 Today D-M-Y

Date of Diagnosis  
15-02-2015 Today D-M-Y

PRIOR RELAPSES

Has the patient ever relapsed after having achieved a first remission prior to entry in the adult study?  
No  
Once  
Twice  
Three times  
Four times

DIAGNOSIS  
Please select patient's diagnosis from the list below

PRIMARY VASCULITIS

Giant Cell Arteritis  
Yes

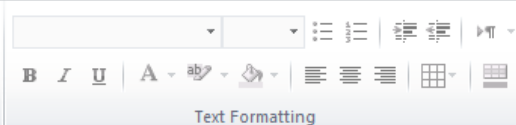
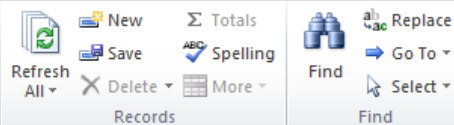
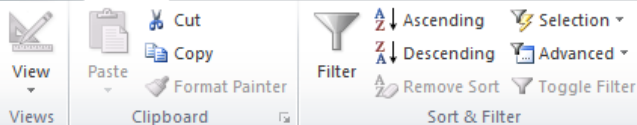
Takayasu's Arteritis  
Yes

Polyarteritis Nodosa  
Yes

Kawasaki disease  
Yes



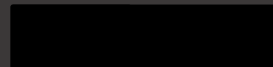
File Home Create External Data Database Tools



Home Patient Entry

CANVASC  
Vasculitis Registry

Hospital ID: 905731071



Date of Birth: 1970/03/11

Gender (F/M): Male

Date Created: 2015/07/20

Physician: Pagnoux

Physician Centre: MSH

Patient Lookup: Selection will appear in header fields

New Patient

Home

Save

Connectory

Entry, Background

Clinical Visit

Biology, LP

Biopsy Results

Imaging, ECG, Echo

Immunology

Drug Treatment

Adverse Events

VDI

Patient Entry

Patient Demographics

Co-morbidities

Reproduction

Smoking/ Drinking

Death

## Diagnosis

## Primary Vasculitis:

- ☐ Behcet's Disease  
☐ Cryoglobulinemic Vasculitis  
☐ Eosinophilic GPA (Churg-Strauss syndrome)  
☐ Giant Cell Arteritis  
☒ Granulomatous with Polyangiitis  
☐ IgA Vasculitis (Henoch-Schonlein Purpura)  
☐ Kawasaki Disease  
☐ Microscopic Polyangiitis  
☐ Polyarteritis Nodosa  
☐ Takayasu's Arteritis

Other:

## Secondary Vasculitis:

☐ Drug-induced (specify):☐ Hepatitis B☐ Hepatitis C☐ HIV☐ Other CTD (specify):☐ Other Infectious (specify):☐ Paraneoplastic (specify):☐ Rheumatoid Arthritis☐ Sjogren's Disease☐ Systemic Lupus Erythematosus

Other (specify):

Save data before clicking:

Background Summary

☒ Patient meets 1990 ACR and/or Chapel Hill Criteria☒ Patient has consented to study☒ Patient is aged >18 years

1990/07/15

Date of first symptoms attributable to vasculitis  
(other than asthma in EGPA)

2007/07/15

Date the patient was first diagnosed

Has the patient ever tested positive for ANCA? Yes

If YES, specify the type in IF C

Other IF: 

If YES, specify the type in ELISA PR3

Other ELISA: Has the patient ever relapsed after having achieved  
a first remission prior to entry in the study?

If YES, specify the date(s) of all previous relapse(s):

1. Relapse period. Onset date 2011/01/15 -  End date
2. Relapse period. Onset date 2012/08/08 -  End date
3. Relapse period. Onset date 2013/06/06 -  End date
4. Relapse period. Onset date  -  End date

Record: 1 of 1 No Filter Search


## Brainworks Workflows – Adult Patient

### Adult Patient – Screens



#### Launching a patient's visit

**\*\*Observe the Green Banner for an Adult Patient Visit\*\***

001 - BrainWorks Coordinator | [Home](#) | [Logout](#)







BRAINWORKS  
The International Childhood  
CNS Vasculitis Outcome Study



pediatric  
rheumatology  
european  
society

Alberta Children's Hospital



 [Patient](#)  
 [User](#)  
 [Site](#)

Questions ? Contact [BrainWorks](#)

Patient: 001-065    Visit Info: 1 (Baseline) - 2010-01-01    Visit number: 1 (Baseline) - 2010-01-01    [GO](#)    [Add visit](#)

Study Log

Diagnosis   Patient Info   Biospecimen Checklist   Clinical Features   Laboratory Markers   Imaging   Brain Biopsy   Treatment   Outcome Measures

Study Log

[Edit](#)

Status: Active (from 2014-10-15)

Centre: 001-Hospital for Sick Children, Toronto

Date of birth: 1995-01-15

Date of diagnosis: 2010-01-01

Informed consent obtained: Yes

Participation in other network studies: No

Primary enrolling physician at participating center: ● Rheumatologist

Diagnosing Institute:

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# CanVasc/VCRC Toronto-led studies

- IBD and vasculitides
- GPA cardiac manifestations (with VCRC)
- Genetic + cytoflux study (K. Siminovitch)



## Vasculitis Patient-Powered Research Network

A partnership of the Vasculitis Clinical Research Consortium and the Vasculitis Foundation



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# V-PPRN Research Studies

The goal of the V-PPRN research program is to conduct high-quality studies that will improve the care and the health of patients with vasculitis by exploring research questions that matter most to patients and advance medical knowledge about vasculitis.

The V-PPRN is currently conducting the following studies in partnership with the [Vasculitis Clinical Research Consortium](#). These studies seek to address research questions that are important to both patients and researchers.



## VascWork Study

Although much progress has been made towards finding better medical therapies to treat vasculitis, patients with vasculitis often must manage substantial disease and treatment burdens. Patients with systemic vasculitis may have high rates of work disability and significant loss of personal income from employment. This study will ask questions about:

- **Employment status** (Do patients have to take a prolonged sick leave?)
- **Work productivity** (How many patients have to adjust their work because of the physical demands of the job?)
- **Income** (How many patients have a loss of income following the diagnosis of their disease?)

[Learn more about this study >](#)



## The ANCA Vasculitis Questionnaire (AAV-PRO®)

We are developing and validating a questionnaire to assess quality of life in patients with ANCA-associated vasculitis (AAV). Patients with AAV have inflammation in the small blood vessels leading to involvement of a range of organs, for

# Ready for...

More studies and activities...

+ More centers to join VCRC...

+ Randomized controlled trials...

---

= More fun!

**Thank you!!!**

