The Canadian Task Force on Adolescents and Young Adults with Cancer

News Flash

March, 2017

Definition of a Task Force

"Temporary group of people formed to carry out a specific mission or project, or to solve a problem that requires a multi-disciplinary approach." (businessdictionary.com)

The Canadian Task Force on Adolescents and Young Adults with Cancer was formed in 2008, with funding from the Canadian Partnership Against Cancer and the support of C17, the consortium of Canadian pediatric cancer centres. The Task Force and its many volunteers accomplished a great deal, some of which is listed in the chart below. See page 3 for a complete list of the many individuals who generously donated their "blood, toil, tears and sweat", to quote Winston Churchill. In particular, the founding Chairs of the Task Force are to be applauded as the driving forces behind the Task Force: Ronnie Barr, Paul Rogers, and Brent Schacter. The legacy of the Task Force will live on not just in the advances made for better care for AYA with cancer, but in the awareness raised and the many collaborations established. Well done, everyone!
**Task Force facts by the numbers …**

15 working groups at work during 2008-2017

98 individuals who volunteered to participate, many in more ways than one, meaning $1 million in pro bono work provided each year

110 teleconferences between Chairs and staff

3 stakeholder workshops (that's a lot of networking opportunities)

6 annual meetings of members held between 2009 and 2014

53 posters prepared and presented (not counting those prepared by individual members)

45 PowerPoint presentations prepared and delivered

7 publications by members on behalf of the Task Force, and untold #'s of in-house reports

12,849,119,232 bytes of files created, or 11.9 GB - good thing it's not paper - representing 14,582 files, 1,178 folders

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**And in with the new … the AYA National Network**

The Canadian Partnership Against Cancer (CPAC) funding for the Task Force will end on March 31, 2017. In an attempt to better engage the Canadian healthcare system, CPAC will instead support an AYA National Network which will serve as a national forum, with representatives invited from each provincial and territorial cancer agency and Ministry of Health, and including patient and family representatives, to identify and prioritize gaps in care and recommend strategies to improve health care delivery for AYA with cancer. Dr. Paul Grundy, one of the current Task Force Chairs, and CPAC's Expert Lead for Pediatric, Adolescent and Young Adult Oncology will Chair this new network. It is hoped that many of you will agree to participate in the various working groups which will support the Network Committee. It is expected that current initiatives including system performance measures, psychosocial care including screening for distress, oncofertility and clinical trials will continue to be a focus for the new Network.

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**Remember to check systemperformance.ca on April 21 for the AYA Cancer System Performance Report!**
**Task Force volunteers, 2018-2017**

### 2008-2012

<table>
<thead>
<tr>
<th>WG#1 Survey of services</th>
<th>WG#2 - Transitions</th>
<th>WG#3 Recommendations</th>
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<tbody>
<tr>
<td>Norma D’Agostino</td>
<td>Ronnie Barr</td>
<td>Conrad Fernandez</td>
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<td>Abha Gupta</td>
<td>Norma D’Agostino (lead)</td>
<td>Graeme Fraser</td>
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<td>Anne Klassen</td>
<td>Sharon Guger</td>
<td>Carolyn Freeman</td>
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<td>Megan McLeod</td>
<td>Paul Nathan</td>
<td>Eva Grunfeld</td>
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<td>Raveena Ramphal (lead)</td>
<td>Annette Penney</td>
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<td>Sheila Pritchard</td>
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<td>Krista Wilkins</td>
<td>Brent Schacter (lead)</td>
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WG#4 Pediatric -adult communication

Ronnie Barr
Geoff Cuvelier
Leanne Kitchen-Clarke
Paul Rogers (lead)
Brent Schacter
Simon Sutcliffe

<table>
<thead>
<tr>
<th>WG#5 - Research priorities</th>
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<tbody>
<tr>
<td>Ronnie Barr (co-lead)</td>
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<td>Sharon Campbell</td>
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<td>Graeme Fraser (co-lead)</td>
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<td>Melanie Keats</td>
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<td>David Malkin</td>
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<td>Ralph Meyer</td>
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<td>Louise Parker</td>
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<td>Stuart Peacock</td>
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<td>Rochelle Yanofsky</td>
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<td>Carol Portwine</td>
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### 2013-2017

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<thead>
<tr>
<th>Active Care Working Group</th>
<th>Follow-up Care Working Group</th>
<th>Clinical Trials Working Group</th>
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<tbody>
<tr>
<td>Sylvie Aubin</td>
<td>Anne Marie Charpentier</td>
<td>Lesleigh Abbot</td>
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<td>Piotr Czaykowski</td>
<td>Beth Kapusta</td>
<td>Ronnie Barr (lead)</td>
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<td>Abha Gupta</td>
<td>Melanie Keats (lead)</td>
<td>Sian Bevan</td>
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<td>Andrea Johnson</td>
<td>Paul Nathan</td>
<td>Geoff Cuvelier</td>
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<td>Sarah McKillop</td>
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<td>Raveena Ramphal (lead)</td>
<td>Sheila Pritchard</td>
<td>Annette Hay</td>
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<td>Paul Rogers</td>
<td>Mike Mills</td>
<td>Jean-Marie Leclerc</td>
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<td>David Szwajcer</td>
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<td>Sarah McKillop</td>
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<td>Krista Wilkins</td>
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<td>Ralph Meyer</td>
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<td>Denis Soulières</td>
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**Cont’d**
## Distress Screening Working Group
- Norma D’Agostino (lead)
- Sylvie Aubin
- Vicky Breakey
- Ann Klassen (lead)
- Mike Lang
- Andrea Johnson
- Alyssa Macedo
- Antoinette Anazodo
- Fiona McDonald
- Michael Osborne
- Susan Palmer
- Pandora Patterson (AUS lead)
- Michael Noory

## Prevention and Screening WG
- Ronnie Barr
- Mihir Bhatt
- Geoff Cuvelier
- Graeme Fraser
- Mira Goldberg
- Eva Grunfeld
- Melanie Keats
- Stacey Marjerrison (lead)
- Kristen Marr
- Raveena Ramphal
- Paul Rogers
- Brent Schacter

## Governance Committee
- Leanne Kitchen-Clarke (Chair)
- Duncan Pike
- Brent Schacter
- Simon Sutcliffe
- Ashley Turner

## Advisory Committee
- Heidi Adams
- Brad Pollock
- Simon Sutcliffe (Chair)
- Jeremy Whelan

## Oncofertility Working Group
- Ronnie Barr (lead)
- Nancy Baxter
- Melissa Beilhartz
- Norm Berberich
- Gillian Bromfield
- William Buckett
- Karen Buzaglo
- Lorne Cooper
- Jill Dudebout
- Liz Ellwood
- Shu Foong
- Janet Fraser
- Bronwyn Garand-Sheridan
- Karen Glass
- Ellen Greenblatt
- Paul Grundy
- Abha Gupta
- Joan Hamilton
- Jessica Holmes
- Aaron Jackson
- Anne Katz
- Jillian Mooney
- Michael Neal
- Sheila Pritchard
- Jeff Roberts
- Maria Velez
- Teresa Woodruff
- Samantha Yee

## System Performance Measurement Working Group
- Paul Rogers (lead)
- Ronnie Barr
- Tim Buckland
- Brenda Canitz
- Karine Chalifour
- Carol Digout
- Annette Flanders
- Mark Greenberg
- Paul Grundy
- Sumit Gupta
- Chad Hammond
- Petr Kavan
- Kristen Marr
- Mary McBride
- Michael Palumbo
- Stuart Peacock
- Jason Pole
- Brent Schacter
- Susan Schroeder
- Young Soo Rho
- Amirrtha Srikanthan
- David Szwajcer

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**Of interest ...**

"Against a Singular Message of Distinctness: Challenging Dominant Representations of Adolescents and Young Adults in Oncology" *Journal of Adolescent and Young Adult Oncology*. Available at [http://bit.ly/2m8PUvv](http://bit.ly/2m8PUvv) until April 10