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# Patient transition after active cancer treatment – how do we share care?

Survivorship Forum, June 8, 2016

Presenters:

Betty Lam

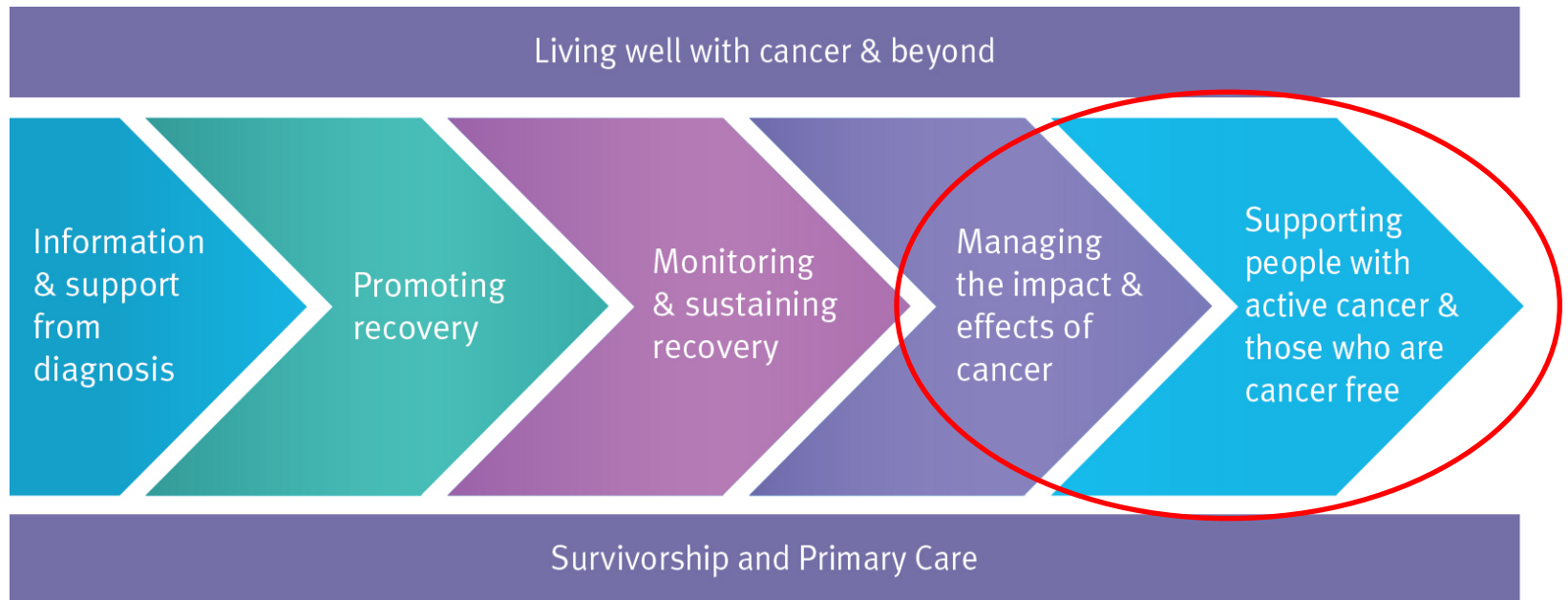
Shaun Lorhan

Andrea McIntosh



# The Survivorship Pathway

Our focus today is on the post treatment needs



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# Cancer in BC today

- Prevalence is growing by ~3% per year
- 203,908 survivors in BC – 5% of the population
  - More than 50% live in rural or remote BC
- 65% of adults and 80% of children diagnosed with cancer are expected to live at least five years post-diagnosis
- 37,347 new cases/year expected by 2028



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BC Cancer Agency. *BC Cancer Statistics – Projected Cancer Statistics*. Retrieved May 15, 2015 from [http://www.bccancer.bc.ca/statistics-and-reports-site/Documents/BritishColumbia\\_20132028.pdf](http://www.bccancer.bc.ca/statistics-and-reports-site/Documents/BritishColumbia_20132028.pdf)  
BC Cancer Agency. *BC Cancer Statistics - Prevalence*. Retrieved May 15, 2015 from <http://www.bccancer.bc.ca/health-info/disease-system-statistics/bc-cancer-statistics/facts-and-figures>

# 2015 Prevalence rates of cancer in BC

	# of alive cancer patients up to 2015	Health Authority population in 2015	Prevalence of cancer by region
Interior	43,928	736,826	5.96%
Fraser	75,218	1,733,902	4.34%
Vancouver Coastal	58,945	1,157,116	5.09%
Island	48,927	767,505	6.37%
Northern	12,252	290,558	4.22%
<b>Province</b>	<b>239,270</b>	<b>4,685,907</b>	<b>5.11%</b>



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<http://www.bcstats.gov.bc.ca/StatisticsBySubject/Demography/PopulationProjections.aspx>

CAIS warehouse tables – H.I.M data request from November 5<sup>th</sup> 2015

# Shared care of patients post active cancer treatment



- Oncology perspective
- Primary care provider perspective
- Patient perspective



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# Stakeholder Analysis: Identified Gaps/Needs

Needs	Frequency of report
Coordination/continuity of care	83
Psychosocial support	63
Access/awareness of resources	39
Access/reliable information	27
Prevention: exercise/nutrition	17
Return to work/Finances	17
Other	6



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# Stakeholder Analysis: Content for Recommended Solutions

Needs	Frequency of report
Psychological/emotional support – coping strategies	34
Lifestyle: wellness, nutrition, complimentary therapies, exercise	30
Resource information – who to contact when and for what	23
Long term side effects: pain, fatigue, memory loss	13
Practical: return to work, finances, transportation	12
Relationships: family, friends, sexual	9
Spiritual: death and dying	5



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# Betty's story



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# How do we share care?

## Resources for patients and care providers



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# Resources for Patients

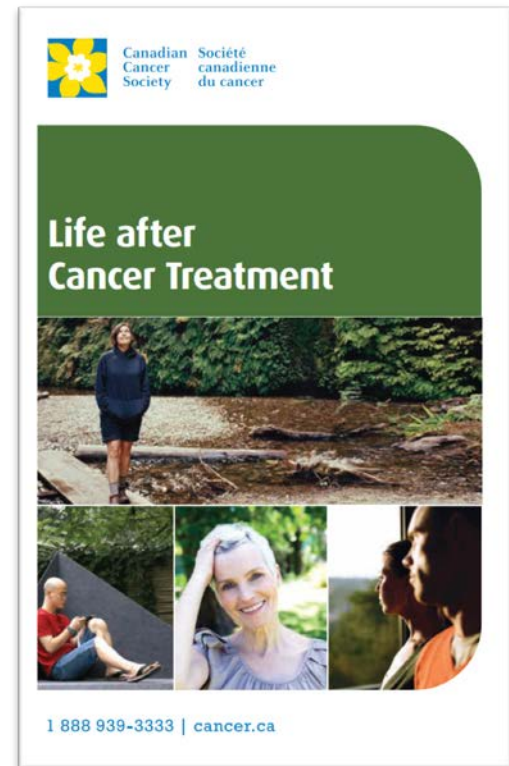
- General Survivorship Resources
- Emotional Support
- Diet and Nutrition
- Physical Activity and Exercise
- Returning to Work
- Financial Issues



# Resources for Patients

## General Survivorship Resources

- BC Cancer Agency Library
- Life After Cancer: Web pages for patients, BC Cancer Agency
- Life After Cancer Treatment publication, Canadian Cancer Society



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# Resources for Patients

## Emotional Support

- Patient and Family Counselling, BC Cancer Agency
- Peer Support
  - In-person support groups, BC Cancer Agency
  - Cancer Chat Canada, De Souza Institute
  - CancerConnection.ca, Canadian Cancer Society
  - New Normal, Canadian Cancer Society
- Patient Handouts: Coping with Cancer, BC Cancer Agency



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# Resources for Patients

## Diet and Nutrition

- Oncology Dietitian Services, HealthLink BC, 8-1-1
- Patient Handouts: Oncology Nutrition, BC Cancer Agency
- Life After Cancer, BC Cancer Agency webpages
- The ELLICSR Kitchen, Princes Margaret Hospital
- MyHealthConnect-Oncology



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# Resources for Patients



## Physical Activity and Exercise

- Physical Activity Line, Healthy Families BC
- Life After Cancer: Be Active webpage, BC Cancer Agency
- Finding a Physiotherapist, Physiotherapy Association of BC
- MyHealthConnect-Oncology



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# Resources for Patients

## Returning to Work

- Vocational Rehabilitation Counsellor
- Cancer and Returning to Work: A Practical Guide for Cancer Patients, BC Cancer Agency

## Financial Information

- BC Cancer Agency webpages
  - Information on health insurance coverage
  - Programs to help with medical costs
  - Patient handouts and videos



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# Resources for Primary Care Providers

- BC Cancer Agency Website
  - Cancer Information (A to Z list of cancers)
  - Cancer Management Guidelines
- Oncology clinical practice guidelines and protocols
  - Breast
  - Colorectal
  - Female genital tract
  - Upper gastrointestinal cancers (Family Practice Oncology Network)



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# Resources for Primary Care Providers

- Ongoing education opportunities
  - Annual Survivorship Forum
  - Family Practice Oncology Network (FPON)
    - Continuing Medical Education opportunities
      - Family Practice Oncology CME Day (Nov 19, 2016)
      - Monthly webcasts
      - Community workshops
    - GPO training
    - Journal of Family Practice Oncology



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# Resources: Our Current State

- Many useful survivorship resources exist
- Yet we still have some work to do:
  - Continue to raise awareness of resources and increase patient and care provider access
  - Continue to better understand and address challenges related to the transfer of care between oncology and community based primary care providers



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# Developing a Shared Care Action Plan

Initiative to better understand the challenges related to the shared care of cancer patients at the end of cancer treatment, and opportunities for improvement

	Victoria	Surrey	Vancouver	Abbotsford	TOTAL	
Family Physician/General Practitioner	26	4	22	7	59	49%
Oncologist	7	4	4	5	20	17%
General Practitioners in Oncology	0	1	2	1	4	3%
Nurse Practitioners	0	1	3	0	4	3%
Nurse	0	1	0	4	5	4%
Patient	3	1	6	1	11	9%
Other	6	5	4	3	18	15%
<b>TOTAL</b>	<b>42</b>	<b>17</b>	<b>41</b>	<b>21</b>	<b>121</b>	



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# Engagement Sessions: Current successes

- Some aspects of communication between oncology and primary care
- Ongoing primary care available to cancer patients
- Expertise and support offered by the BC Cancer Agency
- Education opportunities offered through the Family Practice Oncology Network (FPON)

*“The discharge letter to primary care and follow-up protocol is helpful to the family doctor” (Victoria participant)*



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# Engagement Sessions:

## Prioritized Opportunities for Improvement

1. Standardize discharge summary and follow-up care plans
2. EMR integration and interoperability
3. Enhance trust and timely communication between oncology and primary care providers
4. Increase patient empowerment
5. Introduce a complex care code to provide follow-up cancer care
6. Establish a centralized recall system



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# Engagement Sessions:

## Prioritized Opportunities for Improvement

7. Reduce the number of unattached cancer patients
8. Increase patient and provider awareness of resources available through the BCCA
9. Include oncology in the Rapid Access the Consultative Expertise (RACE) line for easy access to specialists
10. Provide added support to patients as they transition from cancer care to primary care
11. Develop a palliative care network and strategy



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# Action Plan Next Steps: Regionally

- A summary of each regional engagement session to be presented to:
  - Cancer centre leadership team/champions
  - Local divisions of family practice
- Determine regional priorities and partnership opportunities

*“As a result of attending this engagement session, I will attend more cancer related CME, connect more with oncologists, listen to patients more.” (Abbotsford participant)*



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# Action Plan Next Steps: Provincially

- Prepare final report and action plan
- Establish provincial priorities and direction

*“Happy that BCCA is reaching out to GPs re continuing care for the cancer survivors. They have done a good job educating GPs, with consult letters, BCCA website and FPON network. Now is the time for looking after the longer term survivors.” (Vancouver participant)*



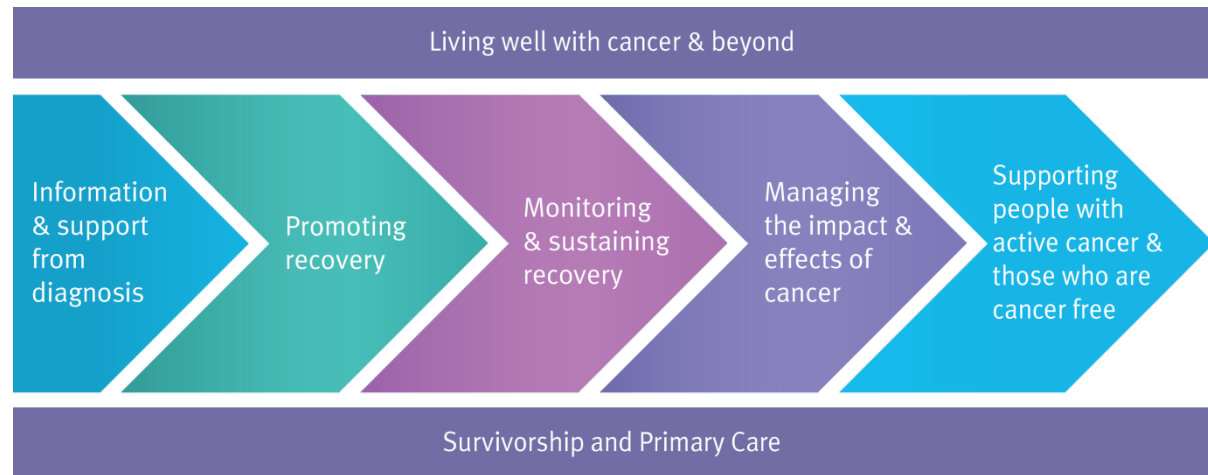
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# Future Direction



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## Appendix – Patient Resources

BC Cancer Agency Library [www.bccancer.bc.ca/our-services/services/library](http://www.bccancer.bc.ca/our-services/services/library) : libraries are located at each of the 6 regional cancer centres and available to all patients, members of the public and health care providers. They provide a number of tools including an online catalogue, pathfinders that include resources on a specific topic (such as Life after Cancer), and a page that lists helpful survivorship websites. Library staff members are available to help people find the information they're looking for, either in person or over the phone, and can loan resources free of charge through mail for those who are unable to visit one of the [BC Cancer Agency's regional centres](#) in person.

Life after Cancer webpages: [www.bccancer.bc.ca/health-info/coping-with-cancer/life-after-cancer](http://www.bccancer.bc.ca/health-info/coping-with-cancer/life-after-cancer) Published by the BC Cancer Agency Survivorship Program, the webpages outline information and resources related to finding a new normal after cancer treatment, what to expect with follow-up after cancer treatment, as well as information on health and wellness and cancer prevention information.

Life after Cancer Treatment Booklet: <http://www.cancer.ca/>

Available free of charge online, or by mail. The booklet covers a range of topics including emotions associated with returning to a “normal” life, the range of reactions and feelings often experienced after cancer treatment, things to consider to manage follow-up care, lingering or longer term side effects and suggestions of how to cope with them, and finding meaning after cancer treatment.

Patient Handouts: <http://www.bccancer.bc.ca/health-info/coping-with-cancer/emotional-support/resources>

Created by the BC Cancer Agency, various patient handouts are available that look at emotions and behaviours related to stress that people can experience during or after cancer treatment, and possible strategies to alter or change them. This includes strategies such as deep breathing exercises, strategies to help with sleep, and progressive muscle relaxation.

Patient and Family Counselling: located at each of the 6 regional cancer centres. Provides support during and after cancer treatment. This service is available to anyone in BC who has received a diagnosis of cancer, as well as those supporting them. Counselling is available to individuals, couples, and families, either in person or over the phone. **Patients who have received cancer treatment are able to *start* accessing professional counselling up to 18 months after their cancer treatment has finished.** The services are solution-focused, and are limited to addressing challenges related to cancer. This includes issues such as fear that the cancer will come back, changes in relationships with family members or friends as a result of cancer, and how to find a “new normal” now that treatment has finished.

In-person support groups: Cancer centres generally offer monthly support groups, sometimes specific to particular types of cancer. Also offered are facilitated groups to help with stress reduction, including mindfulness based stress reduction, relaxation and stress management, and therapeutic touch. Availability varies by location. For a schedule of support groups offered, contact the Patient and Family Counselling Department at the closest [BC Cancer Agency regional centre](#).

Cancer Chat Canada: <https://cancerchat.desouzainstitute.com/> Patients can register for these time-limited, professionally-facilitated online support group with peers. The online groups meet once per week for 90 minutes in a live “chat” room on the internet, typically for 10 weeks

CancerConnection.ca: [www.cancerconnection.ca](http://www.cancerconnection.ca) online community is available to people diagnosed with cancer and their family members or support person at any point during the cancer experience: diagnosis, during treatment, or after treatment. This site allows people to connect with others who understand their situation. It has discussion forums, online groups, opportunities to post blogs, and also provides a way to exchange messages with other members to share emotional support and personal experience. Trained moderators ensure the online community is safe and supportive.

New Normal: [1-800-822-8664](tel:1-800-822-8664) or [newnormal@bc.cancer.ca](mailto:newnormal@bc.cancer.ca) A telephone based peer support program, currently for patients who have completed treatment for breast or colorectal cancer. This program was recently introduced and is being piloted by the Canadian Cancer Society in partnership with the BCCA Survivorship Program.

*HealthLink BC – Oncology Dietitian Services; Dial 8-1-1 from anywhere in BC:* This is a free service where patients are able to access nutrition information and resources related to cancer from Registered Dietitians. The service is available over the phone and online. An online fact sheet provides a helpful overview on how to eat well after cancer and can be found here: <http://www.healthlinkbc.ca/healthyeating/cancer-survivors.html>

*BC Cancer Agency Oncology Nutrition* <http://www.bccancer.bc.ca/health-info/coping-with-cancer/patient-resources>: Registered dietitians have created a number of resources for cancer patients. A range of topics are covered including food ideas to help manage diarrhea or constipation, and a nutrition guide for women with breast cancer.

### *The ELLICSR Kitchen*

[https://www.ellicsr.ca/en/clinics\\_programs/ellicsr\\_kitchen](https://www.ellicsr.ca/en/clinics_programs/ellicsr_kitchen) Created by Princess Margaret Cancer Centre in Toronto, Ontario, this website aims to support people impacted by cancer in managing a healthy diet. Video demonstrations and simple, delicious recipes can be found online.

### *The Physical Activity Line*

<http://physicalactivityline.com/index.php/cancer/exercise-cancer>. A

resource developed by qualified exercise professionals, this phone line and website provides a practical overview of considerations and suggestions for people who are going through, or have gone through cancer and are looking to be active. This includes things to do prior to exercising, what types of activities cancer patients may wish to consider, and tips for success. Patients are also able to call the physical activity line for individualized information.

*Physiotherapy Association of British Columbia* <http://bcphysio.org/>: Some people may wish to seek out a physiotherapist in their city or town to help develop an activity plan or work on specific challenges they are experiencing. The physiotherapy association of British Columbia provides a way to search for a physiotherapist in a particular community who specializes in oncology.

*Vocational Rehabilitation Counsellor* An appointment with the Vocational Rehabilitation Counsellor can be scheduled by [contacting the closest regional cancer centre](#): A vocational rehabilitation counsellor from the BC Cancer Agency, Maureen Parkinson, is available to speak with patients that require assistance with work related issues. This resource is available to people during or after receiving cancer treatment. The counselling can include assisting to develop a plan to return to work, career exploration, clarifying insurance benefits, information on human rights and resources in the community, job search instruction and counselling related to life planning and goal setting.

*Cancer and Returning to Work – A Practical Guide for Cancer Patients*  
[http://www.bccancer.bc.ca/coping-and-support-site/Documents/Cancer\\_Returning%20to\\_Work\\_Manual\\_Interactive%20%283%29.pdf](http://www.bccancer.bc.ca/coping-and-support-site/Documents/Cancer_Returning%20to_Work_Manual_Interactive%20%283%29.pdf) : Developed by the vocational rehabilitation counsellor at the BC Cancer Agency, this resource is designed for people who are considering or planning to return to work after cancer treatment. The workbook includes practical considerations and tips on assessing readiness to return to work, including exercises to complete to better understand and plan for return to work. It also provides strategies for enhancing your workplace experience, and how to manage your transition back to work after a cancer experience. This resource is available free of charge online, or hard copies can be ordered for a small fee



### *Financial & Healthcare Coverage Information*

<http://www.bccancer.bc.ca/health-info/coping-with-cancer/practical-support/resources> : The BC Cancer Agency has created webpages, patient handouts and supporting videos related to finances during and after treatment. Topics covered in these resources include but are not limited to practical and financial support for people with advanced cancer, financial assistance for prescription drugs, tools to help organize your finances and a list of existing financial support programs.

## ***Appendix – Resources for Providers***

*Types of Cancer Information:* <http://www.bccancer.bc.ca/>

From the BC Cancer Agency homepage, you will see a drop down menu where you are able to access information about different types of cancer. Included information not only focuses on diagnosis, staging and treatment, but may also include information on recommended guidelines for follow-up care and surveillance after cancer treatment.

*Cancer Management Guidelines:* <http://www.bccancer.bc.ca/health-professionals/professional-resources/cancer-management-guidelines>

*Oncology clinical practice guidelines and protocols*

<http://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/oncology> AND <http://www.bccancer.bc.ca/health-professionals/networks/family-practice-oncology-network/guidelines-protocols>

*Family Practice Oncology Network* <http://www.bccancer.bc.ca/health-professionals/networks/family-practice-oncology-network>

Provides education opportunities in a variety of ways to improve the continuity and transition of care between the BC Cancer Agency and community based primary care providers. Current activities include:

- offering Continuing Medical Education opportunities (CME day, accredited monthly webcasts in partnership with UBC's division of continuing professional development, and workshops offered in the community in partnership with UBC Continuing Professional Development – workshops can include small group, case based learning to support family physicians in their role along the cancer care continuum) <http://ubccpd.ca/oncology/community>
- a [GPO Training Program](#) for primary care providers working within oncology to strengthen oncology skills and build valuable contacts and confidence
- [Journal of Family Practice Oncology](#); published twice a year, the journal highlights research and initiatives to keep family physicians informed and promote awareness of resources and opportunities.