



ADOLESCENT AND YOUNG ADULT CANCER PRIORITY SETTING PARTNERSHIP



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#AYACancerPSP

*To join the mailing list or submit content for the next newsletter,
email Brianna Henry at brianna.henry@ucalgary.ca*

A Message from the Co-Leads



Perri Tutelman, PhD



Chantale Thurston



Fiona Schulte, PhD

It is adolescent and young adult (AYA) cancer awareness week! In recognition of this week, we are excited to share some updates on the AYA Cancer Priority Setting Partnership (PSP) project with the community.

It has been a busy start to the year for the AYA Cancer PSP. We have been hard at work processing the research questions submitted in the first AYA Cancer PSP survey. There were over 1,900 research questions submitted! We are hearing just how many uncertainties and priorities there are for AYA cancer research in Canada. We are currently working on organizing and summarizing the research questions that were submitted and look forward to sharing them with you in an interim prioritization survey coming soon.

In this edition of the AYA Cancer PSP newsletter we introduce you to new members of the team, share news from our partner organizations, and provide updates from the broader AYA cancer community. Be sure to check out the various events and opportunities taking place over the next few months.

Thank you for your ongoing support!

Perri, Chantale & Fiona
AYA Cancer PSP Co-Leads

Where We're At

1

Create Steering Group

Composed of equal representation of patients, caregivers, and clinicians.
*The first Steering Group meeting was held on April 18, 2023.



2

Survey #1: Gather Evidence Uncertainties

Patients, caregivers, and clinicians will respond to a survey that asks what questions they want answered by research.



3

Summarize Responses Gathered

All survey responses will be sorted and summary questions will be created. This is the long list of questions.



4

Evidence Checking

The long list of questions is checked against existing research evidence. Any questions that have been answered will be removed.

5

Survey #2: Interim Priority Setting

To reduce the remaining long list, patients, caregivers, and clinicians will vote on the most important questions. This is the short list of questions.

6

Final Workshop

The highest ranked 25-30 questions are discussed. Patients, caregivers, and clinics agree the "Top 10" list of priorities.

7

Dissemination

The Top 10 is announced.

Welcome to the Team!

Tristyn Ranger

Information Specialist



Tristyn Ranger is a research assistant with Dr. Fiona Schulte at the University of Calgary and is the Information Specialist for the AYA Cancer PSP. Tristyn graduated with a BSc Honours in Psychology from UBCO and has lived experience as a cancer survivor since his diagnosis in 2017. He has been continuously involved with the cancer community for the last 7 years, working alongside various organizations and with families navigating a recent diagnosis. Tristyn is thrilled to contribute to a project and field that he is passionate about.

Mackenzie Jansen

Steering Group Member



Mackenzie has been a dedicated nurse since 2006 and is a Clinical Nurse Specialist for the Adolescent and Young Adult Program at CCMB. Mackenzie is part of a multidisciplinary team that provides specialized support to young cancer patients. Additionally, Mackenzie is collaborating with her team on an oncofertility initiative, improving access to timely fertility and fertility-related resources, developing clinical pathways, and providing educational resources for patients and healthcare providers. She is also in her final year of a Master's in Nursing program at the University of Calgary.

It is AYA Cancer Awareness Week!

This week (April 1-5, 2024) is Adolescent and Young Adult (AYA) Cancer Awareness Week. Each year during the first week of April the cancer community raises awareness about the unique challenges faced by AYA patients and survivors. Follow along on social media using the hashtag #AYAAware.



**APRIL
1-5
2024**

AYA CANCER AWARENESS WEEK



Canadian Cancer
Advocacy

www.ayacancerpsp.ca

#AYAAware #AYACancerPSP



CANCER
PRIORITY SETTING
PARTNERSHIP

AYA CAN APRIL COMMUNITY CALL



AYA Can's next Community Call is Monday, April 22 (11am Central Time). Tune in for updates and short presentations for the AYA Community in Canada.

Check out their website for details at www.ayacan.ca



Team Shan

The Fore Shan fundraising golf tournament will be held June 1, 2024 at the Haileybury Golf Club. Now accepting registrations and sponsorships.

Save the date! Team Shan is be hosting a pickleball fundraiser Sept 27-29, 2024 in Huntsville, Ontario.

Contact teamshan@gmail.com for more info.



Colorectal Cancer Canada

On May 16 & 17, 2023, Colorectal Cancer Canada will host their Annual Colorectal Cancer Community Conference. The **free virtual event** will unite patients, survivors, caregivers, advocates, and healthcare professionals.

To register and/or get more info click [here](#).



The Canadian Centre for Applied Research in Cancer Control (ARCC)

ARCC is hosting its 13th annual conference May 16-17, 2024 in person and virtually. Patients are eligible for **free virtual registration**.

Contact Rebecca.Mercer@sunnybrook.ca for a code to register.



Pink Pearl Canada

The Pink Pearl Peer Support Program is now live! This program offers personalized one-on-one peer support for young women facing a cancer diagnosis.

For more information and to apply, click [here](https://bit.ly/pp-peersupport).



Young Adult Cancer Canada (YACC)

YACC Live is a national event that brings together young adult cancer survivors and supporters in their local communities and connect, reconnect, be inspired, and have fun. Watch the webcast on **April 13, 2024** from a meet-up near you or from the comfort of your home.

To register click [here](#).



Patients Redefining the Future of Healthcare

Save the date for the 9th annual Patients Redefining the Future of Health Care in Canada Summit. This event will take place virtually and in person (Toronto, ON) November 19-21, 2024.

Stay tuned for more information.



Congratulations!

Congratulations to AYA Cancer PSP Co-Lead, **Chantale Thurston**, on being selected for the 2024 American Academy of Cancer Research (AACR) Scientist↔Survivor Program!

Chantale will be attending the AACR meeting in April 2024 to receive specialized training on cancer research, survivorship, advocacy, and public policy.



In the News

Steering Group member, **Vinesha Ramasamy**, was interviewed on CTV News about her work partnering with Women's College Hospital to improve cancer care for underrepresented groups.

To watch the interview click [here](#).



Upcoming Webinar

On April 9th, 2024, Steering Group member, **Vinesha Ramasamy**, will be presenting in a free webinar about navigating cancer as an adolescent or young adult.

Click [here](#) to register.



Passionate about advancing health research in Canada? Become a member of one of **CIHR's Institute Advisory Boards**.

Apply by **April 25, 2024**



Apply to join a Canadian Institutes of Health Research (CIHR) Advisory Board

The CIHR Institute of Cancer Research is seeking a **patient representative** for their Institute Advisory Board. Institute Advisory Board members provide advice and guidance on the Cancer Research Institute's activities and initiatives.

If you are interested, e-mail them at cihr.icr@uhn.ca. Application deadline is **April 25**.

Canadian Cancer
Trials Group



Canadian Cancer Trials Group (CCTG) Patient Representative Volunteer Role

The Canadian Cancer Trials Group is currently seeking applications for Patient Representatives for the **Hematology, Breast, Genito-Urinary, and Gynecologic** Disease Site Committees. The role of Patient Representatives is to represent the perspective of patients and their families in the development and delivery of clinical trials.

For more information and to apply click [here](#).

Opportunity to join CADTH's pan-Canadian Oncology Drug Review Expert Review Committee

The pan-Canadian Oncology Drug Review Expert Review Committee (pERC) is a pan-Canadian advisory body composed of individuals with expertise in cancer drug therapy, drug evaluation and drug utilization, and patient members. pERC makes reimbursement recommendations for oncology pharmaceuticals to the participating federal, provincial, and territorial publicly funded drug programs.

pERC is seeking 4 expert members and 1 patient member to join the committee this year. The full details about each role and the application (nomination) process is on the CADTH [website](#).