



# ADOLESCENT AND YOUNG ADULT CANCER PRIORITY SETTING PARTNERSHIP



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**#AYACancerPSP**

*To join the mailing list or submit to the next newsletter,  
email Brianna Henry at [brianna.henry@ucalgary.ca](mailto:brianna.henry@ucalgary.ca)*

# *A Message from the Co-Leads*

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**Perri Tutelman, PhD**

As the Co-Leads of the Adolescent and Young Adult (AYA) Cancer Priority Setting Partnership (PSP) we are thrilled to launch our first community newsletter! The purpose of this newsletter is to provide updates on our progress, share ways to get involved, and highlight opportunities and events from our community partners.



**Chantale Thurston**

We held our first Steering Group Meeting on April 24th, 2023 and we are delighted to officially announce the members of the AYA PSP Steering Group (see page 5)! The members of the Steering Group are patients, caregivers, and clinicians in AYA cancer from across the country. We are looking forward to working with this group over the next 18 months to oversee the PSP process.



**Fiona Schulte, PhD**

Over the next few months the Steering Group will be working to prepare the first online survey to gather the perspectives of AYA cancer patients, caregivers, survivors, and clinicians about what they want answered by research. We will need your help to make sure we capture the voices of everyone in the Canadian AYA Cancer Community. Stay tuned for more information coming soon.

Thank you for your support of the AYA Cancer PSP!

## *About the Project*

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### **WHAT IS THE AYA CANCER PRIORITY SETTING PARTNERSHIP?**

Each year, nearly 9,200 adolescents and young adults (AYAs) are diagnosed with cancer in Canada. AYAs with cancer have unique medical and psychosocial needs that often go unmet. The AYA Priority Setting Partnership (PSP) is bringing together AYA patients, caregivers, and clinicians to identify the key areas of research that are needed to improve care for AYAs with cancer in Canada. The PSP will result in a list of Top 10 Research Priorities that will guide a new research agenda. We are following the James Lind Alliance Method for this PSP. For more info on the JLA, visit: <https://www.jla.nihr.ac.uk/>

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.

# Meet the Steering Group



**Dr. Perri Tutelman**



**Dr. Fiona Schulte**



**Chantale Thurston**



**Tamara Rader**



**Brianna Henry**



**Dr. Cheryl Heykoop**



**Emily Gallant**



**Dr. Evan Taylor**



**Lexy Dobson**



**Lorna Larsen**



**Marlie Smith**



**Michelle Blue**



**Nadia Wendowsky**



**Dr. Mohammad Abdelaal**



**Dr. Sapna Oberoi**



**Stefanie Del Gobbo**



**Tim Buckland**



**Vinesha Ramasamy**

## Research Team

**Dr. Jackie Bender**  
**Dr. Kathryn Birnie**  
**Dr. Lindsay Jibb**  
**Dr. Melanie Noel**

**Dr. Sara Beattie**  
**Dr. Sapna Oberoi**  
**Dr. Sheila Garland**

# Our Partners



ON THE TIP OF THE TOES

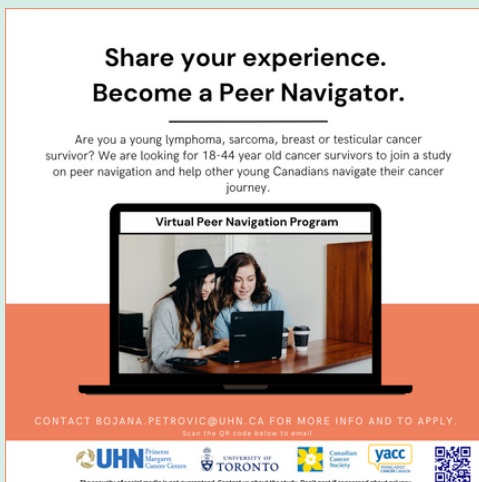
THANK YOU!



## Colorectal Cancer Canada

On May 16 & 17, 2023, Colorectal Cancer Canada will host the 3rd Annual Colorectal Cancer Community Conference. The two half-day free virtual event will unite patients, survivors, caregivers, advocates, and healthcare professionals.

To register and/or get more info:  
<https://tinyurl.com/CCCC-2023>



## AYA Research Opportunity

Are you a young (18-44 years old) lymphoma, breast, or testicular cancer survivor? Join a study on peer navigation and help other young Canadians navigate their cancer journeys.

Contact [Bojana.Petrovic@UHN.ca](mailto:Bojana.Petrovic@UHN.ca) for more info/to apply.



## AYA CAN

AYA Can's next Community Call is Monday May 15, at 2pm EST. Tune in for updates and short presentations for the AYA Community in Canada.

Check out our website for details at  
[www.ayacan.ca](http://www.ayacan.ca)