

AYA NEWSLETTER

Adolescent and Young Adult (AYA) Program Newsletter

September 2018

AYA STUDY SPOTLIGHT

Perceptions of and decision making about clinical trials (CT) in adolescents and young adults with cancer

With approximately 7600 adolescent and young adults (AYA), ages 15 to 39, diagnosed with cancer in Canada each year, there is growing interest in understanding why only few AYA are involved with cancer clinical trials compared to children and older adults. Clinical trials (CT) are defined as “research studies that involve people and test new ways to prevent, detect, diagnose, or treat diseases” [1]. This study was conducted to understand the perceptions and attitudes that influence AYA in participating in clinical trials.

To do this, 21 AYA patients with different types of cancer (leukemia, lymphoma, sarcoma, breast and testes) and experiences with CT were interviewed. The top five major themes identified in over 90% of the interviews include:

- 1. Severity of illness and urgency to receive treatment:** Most stated that they would enrol in a trial if their cancer did not respond to the normal treatment, and if their disease was getting worse.
- 2. Trial side effects:** Side effects were interpreted in different ways, where it would either prevent them from enrolling, had no influence, or were disregarded since they would try any treatment regardless of side effects if they were out of options. Half of the participants expressed concerns around long-term and severe side effects and how it could affect their quality of life.
- 3. Recruitment method:** This involves how AYA were approached about trial participation, including the method of approach (in-person, phone), timing of the approach, and who approached them (oncologist, researcher, nurse). Most preferred being approached by their oncologist. There was no preference around timing, although some said they should only be approached if treatment was not working, and avoid approaching those who were just diagnosed due to it being overwhelming.
- 4. Seeking additional information:** This involves how AYA look for additional information. Most people went online, looking for published research on related studies and getting information about the people who run the study.
- 5. Opinion of others:** This was brought up in all of the interviews, relating to how opinions of family members or friends influenced their enrollment decision. Most said that family helped them make a decision, supported them in looking for trial information or helped them stay informed about the trial.

This study suggests that AYAs’ consideration of clinical trials may closely involve their stage of disease and what they believe is best for themselves. We may want to consider involving family in decision-making and helping AYA understand the short and long term implications of CT participation.

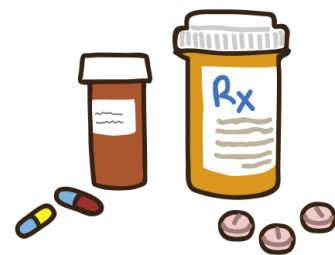
Read the full research paper here: <http://bit.ly/2PN2bpO>

This study was conducted at the Princess Margaret Cancer Centre during the summer of 2018. If you would like to participate in one of our ongoing studies, contact us at aya@uhn.ca

[1] <https://www.nih.gov/research-training/clinical-trials>

To learn more about our research and to view a list of AYA publications:

<http://bit.ly/2n1okU5>



Measuring the Impact of an Adolescent and Young Adult Program on Addressing Patient Care Needs
Published July 2018



MONTHLY COMMUNITY UPDATES

GILDA'S CLUB

24 Cecil St. Toronto, ON
www.gildasclubtoronto.org
416 214 9898



Never Mind Comedy Show with Anna Gustafson

September 12 at 7 PM

Take a break at Gilda's with an amazing stand-up show featuring some of Canada's strongest comic talent! This event is for members aged 16 and up. Feel free to bring guests. For more info and to register for the event, visit <http://bit.ly/2MAebNj>

WELLSPRING



4 Charles St E
Toronto, ON
www.wellspring.ca
416 961 1928

Visit online for upcoming program event dates this month: <http://bit.ly/2sGqCdy>

AYA PROGRAM UPDATES

SEPT 27: AYA CANCER MEET-UPS RESUME

Our monthly AYA meet-ups have returned and we hope to see you there! They will continue to take place every 4th Thursday of the month (with the exception of the December meet-up, which is cancelled). Upcoming meet-ups will take place on the following dates:

- **Thursday, September 27, 2018**
- **Thursday, October 25, 2018**
- **Thursday, November 22, 2018**



Meet-ups take place from 6 to 7:30 PM on the 16th floor, Room 726 at the Princess Margaret Cancer Centre. We encourage participants to RSVP to aya@uhn.ca if they are planning to attend. Pizza will be provided.

COMMUNITY EVENTS & UPDATES

SEPT 24 - 28: RETREAT YOURSELF ADVENTURE



Retreat Yourself Adventure gives young adult cancer survivors and supporters a chance to tackle survivorship issues while ziplining and hiking in Newfoundland on an Adventure that will push their limits and challenge them physically and mentally. **It will be taking place in Gros Morne, NL from Sept 24-28. For more information and registration, visit: <http://bit.ly/2tWCYzT>**

SEPT 26: PINK PEARL LOCAL SOCIAL IN NIAGARA

Pink Pearl Foundation is hosting another local social in Niagara at the Honsberger Estate Winery in Niagara on September 26. The program is free and available to young women facing cancer between the ages of 18 to 40. **For more info & to attend, please RSVP by September 10, 2018 to RSVP@pinkpearloundation.org**



OPPORTUNITY FOR CHINESE AYA ADVOCATES

What was the first thing that came across your mind when you were diagnosed? Did your family and friends know what to do or how to help? Were you looking for someone to connect with?

Here is your chance to speak out about your experience and be an advocate by raising awareness about the impact cancer can have on young adult patients. We are looking for Chinese Canadians who speak Cantonese and Mandarin to participate in a 5 to 10 min phone or in person interview for our upcoming Radiothon Fundraiser in December. If you or your family are open to sharing your story, please contact **Bonnie Ho** at bonnie.ho@thepmcf.ca

HELPING WOMEN WITH METASTATIC CANCER



Melanie's Way is an organization that helps women with metastatic cancer by creating a personalized experience, a "wish" that brings them and their loved ones joy and creates memories. To learn more about the program, visit www.melaniesway.com