

CCSS

*An NCI-funded  
Resource*

# Education Committee PI Meeting

CCSS PI Meeting  
June 10, 2015

# Objectives

- To disseminate study findings to participants
- To educate study participants about
  - Cancer-related health risks
  - Health surveillance recommendations
  - Survivor advocacy/resources
- To promote survivor resiliency/self-advocacy
- To facilitate ongoing participation in research

## *Newsletter*

- Format: 4 page
- Content
  - From the editor
  - Study results
  - Health commentary
  - Survivor vignettes/notes
  - Survivor resources
- Distribution: 1/year

## *Briefs*

- Format: 2 page
- Content
  - Study results
  - Survivor resources
  - COG Guidelines
- Distribution: 2-3/year

- Feb 2014: Fertility
  - Green et al. Fertility of female survivors of childhood cancer. JCO. 2009
  - Green et al. Fertility of male survivors of childhood cancer. JCO. 2010
- April 2014: Cardiovascular risk factors
  - Meacham et al. Cardiovascular risk factors in adult survivors of pediatric cancer. CEBP. 2010

- June 2014: Skin cancer
  - Pappo et al. Melanoma as a subsequent neoplasm in adult survivors of childhood cancer. PBC. 2013
  - Watt et al. Radiation-related risk of basal cell carcinoma. JNCI. 2012
- Jan 2015: Reduced treatment side effects
  - Essig et al. Risk of late effects of treatment in children newly diagnosed with standard-risk ALL. Lancet Oncol. 2014
- April 2015: Exercise and heart health
  - Exercise and risk of major cardiovascular events in adult survivors of childhood HL. JCO. 2014

- New LTFU study leadership.
- Healthy habits help survivors thrive.
  - Armstrong et al. Modifiable risk factors and major cardiac events among adult survivors of childhood cancer. JCO. 2013
- Stroke risk in childhood cancer survivors
  - Radiation, atherosclerotic risk factors, and stroke risk in survivors of pediatric cancer: IJROBP. 2013
- Making healthy changes/resources
- Survivor story: What worked for Elisa

# Future Briefs/Newsletters

- Age-dependent health changes (Hudson)
- Knowledge of affordable care act (Park)
- Auditory complications (Whelan)
- Psychoactive medication use (Brinkman)
- Psychological distress (Brinkman)
- Psychosexual functioning (Ford)
- Genetic testing

## Two Sentence Stem for App

Exercise is medicine! A new LTFU study has shown that participating in vigorous physical exercise may significantly reduce survivors' future risk of heart disease, even if they received heart-damaging treatment to cure their childhood cancer or have other risk factors such as high blood pressure, high cholesterol, or being overweight. *For more information go [HERE](#) (click link).*

## Linked 6-8 Sentence Summary

## Reference



# CCSS App Features

- Klosky et al. Relations between posttraumatic stress and posttraumatic growth in long-term survivors of childhood cancer. *Health Psychol.* 2014
- Jones et al. Exercise and risk of major cardiovascular events in adult survivors of childhood Hodgkin lymphoma. *JCO.* 2014
- Perkins et al. Infections among long-term survivors of childhood and adolescent cancer. *Cancer.* 2014
- Klosky JL et al. Risky sexual behavior in adolescent survivors of childhood cancer. *Health Psychol.* 2014

# CCSS App Features

- Daniel et al. Predictors of colorectal cancer surveillance among survivors of childhood cancer treated with radiation. *Cancer*. 2015
- Kirchhoff et al. Supplemental security income and social security disability insurance coverage among long-term childhood cancer survivors. *JNCI*. 2015
- Park et al. Childhood cancer survivor study participants' perceptions and understanding of the affordable care act. *JCO*. 2015
- Phillips et al. Survivors of childhood cancer in the United States: prevalence and burden of morbidity. *CEPB*. 2015

# CCSS App Impact

- Adherence to production schedule
- Maintenance of library of CCSS features
- Leveraging institutional press releases
- Increasing awareness of newsworthy issues

# Feedback from survivors

- Many topics are depressing. Can you tell us some good news?
- Can you include more info about how to minimize risks?
- Considering forum for to respond to survivor's questions.

# Your thoughts/suggestions?

- Additional topics for Briefs?
- Content for CCSS Newsletter?
- Content for CCSS app?

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