



# 2019

21-23 JUNE

SAN FRANCISCO

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE

## Impact of Alopecia on Quality of Life.

# MASCC/ISOO

Annual Meeting on Supportive Care in Cancer

[www.mascc.org/meeting](http://www.mascc.org/meeting)

Follow us on Twitter: @CancerCareMASCC



#MASCC19

# Disclosures: Prof Fran Boyle

- The Patricia Ritchie Centre, Mater Hospital, North Sydney has trialed scalp cooling devices made by Penguin, Dignitana and Paxman



# Alopecia: a sine qua non for cancer



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Prince of Wales  
Hospital Appeal



# Madarosis: its underrated cousin



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The Scar Project





# And men: often overlooked



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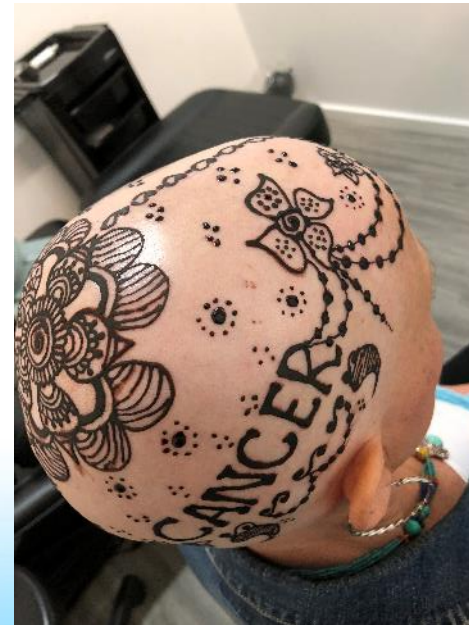
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# And opportunities to experiment



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# If you cannot fix it, why measure it?

- Standard QOL measures used in cancer do not even include hair loss as an item
  - EORTC QLQ C 30
  - FACT-G
- Some Breast Cancer measures do include aspects of body image and its impact on others
  - Br 23 includes
    - Less feminine
    - Less attractive
    - Dissatisfied with body
  - FACT B
    - I am bothered by hair loss



# And PRO-CTCAE may be not much better



Browser tabs: Patient-Reported Outcomes versi x +

Address bar: w/pro-ctcae/download.php

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## NCI PRO-CTCAE™ ITEMS

Item Library Version 1.0  
English  
Form created on 22 June 2019

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**As individuals go through treatment for their cancer they sometimes experience different symptoms and side effects. For each question, please check or mark an ☒ in the one box that best describes your experiences over the past 7 days...**

1. In the last 7 days, did you have any HAIR LOSS?

<input type="radio"/> Not at all	<input type="radio"/> A little bit	<input type="radio"/> Somewhat	<input type="radio"/> Quite a bit	<input type="radio"/> Very much
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# Overview of QOL impact of scalp cooling



- Systematic Review of Scalp cooling studies
  - Most used EORTC QLQ C 30 +/- Br 23
  - Despite improvements in hair preservation, overall QOL impact inconsistent
  - Failure to separate successful cooling vs unsuccessful cooling
- Called for better measurement tools

Marks et al, Br Ca Res Rx 2019



# Can we do better? Hair QOL

95 issues identified in interviews with patients and health professionals in 4 countries.

43 summarised for next phase of testing in 5 themes:

Information / preparedness

Impact on self

Impact on others

Management of hair loss

Regrowth

CHILL consortium.  
Hair QOL Phase 3  
Testing in progress  
In 10 countries.



# Mater Patient Experiences: Focus Groups



Used with permission

- › “I was able to hide my breast cancer diagnosis from my work colleagues and son.”
- › “It helped me take a little control at a chaotic time.”
- › “I have lost a lot of hair, but can get by with using a cap to cover the crown.”
- › “I worried when my hair started to fall out...its important to know what to expect”
- › “The regrowth is very fast – I now look like I have a “Mullet” with thick curly hair on top.”
- › “No-one is cutting me any slack because I don’t look sick!”
- › “I needed more information for my hair dresser: no-one had heard of it”

Shaw J et al , Supp Care Cancer 2016



# Madarosis and QOL

- Focus groups in Australia identified multiple issues

Timing of loss vs scalp hair

Information

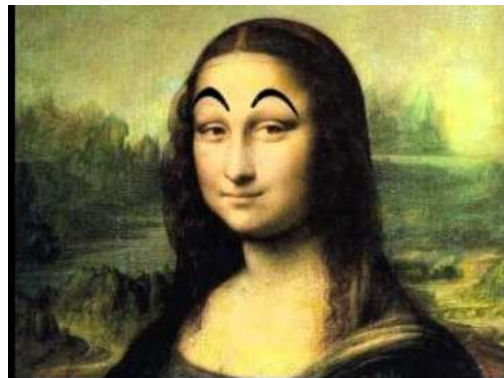
Impact on eye comfort

Impact on self / communication

Impact on others

Management / Regrowth

- QOL tool in development and timeline study



Smith K et al, Support Care Ca, 2018



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# Korean CADs

Chemotherapy- induced Alopecia Distress scale

- 4 subscales
  - Physical
  - Emotional
  - Activity
  - Relationships
- Awaiting validation in other languages



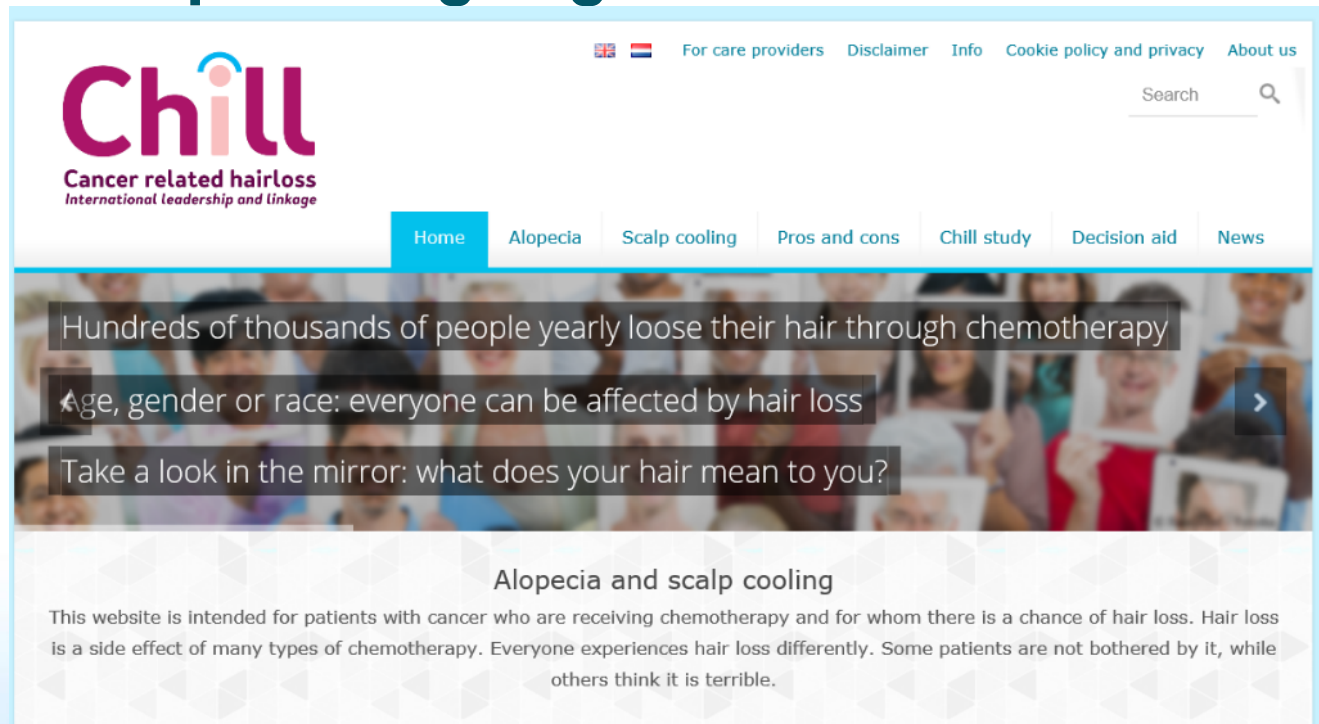
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Cho et al, Annals of Oncology 2013



# Patient decision support.

## www.scalpcooling.org



The screenshot shows the homepage of the Chill website. At the top left is the Chill logo with the tagline "Cancer related hairloss" and "International leadership and linkage". To the right of the logo are flags for the UK and the Netherlands, followed by links: "For care providers", "Disclaimer", "Info", "Cookie policy and privacy", and "About us". A search bar is located on the right side of the header. Below the header is a navigation menu with links: "Home", "Alopecia", "Scalp cooling", "Pros and cons", "Chill study", "Decision aid", and "News". The main content area features a large banner with a background image of a diverse group of people. Overlaid on the banner are three text boxes: "Hundreds of thousands of people yearly loose their hair through chemotherapy", "Age, gender or race: everyone can be affected by hair loss", and "Take a look in the mirror: what does your hair mean to you?". Below the banner is a section titled "Alopecia and scalp cooling" with a paragraph: "This website is intended for patients with cancer who are receiving chemotherapy and for whom there is a chance of hair loss. Hair loss is a side effect of many types of chemotherapy. Everyone experiences hair loss differently. Some patients are not bothered by it, while others think it is terrible."

Chill  
Cancer related hairloss  
International leadership and linkage

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Search

Home Alopecia Scalp cooling Pros and cons Chill study Decision aid News

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Age, gender or race: everyone can be affected by hair loss

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Alopecia and scalp cooling

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