

# Letter from the Chair

Thanks to our Conference Planning Committee and UC Davis for a very successful meeting. We reviewed the conference evaluations closely and appreciate all of the constructive and overall positive feedback. We are looking forward to adding more information to our future meeting, with a new pre-conference workshop focusing on Sexual Concerns, Models, Mission and Measurable Outcomes.

# 2017 Conference Summary

The 2017 Network Conference was held April 6-7, 2017, in Sacramento, CA, with UC-Davis serving as the host institution. Here is a brief snapshot of the conference:

- 55 attendees from 18 states and 3 countries (United States, Singapore, and Sweden)
- 26 members; 5 new regular members; 13 new trainee members; 8 non-members; and 3 speakers
- Sessions included a panel discussion on psychosexual interventions for women with cancer, from development to implementation; female sexual dysfunction; integrative approaches for women with sexual dysfunction after a cancer diagnosis, and NCI funding priorities for 2017. Invited speakers received rave reviews by attendees who completed the evaluation.
- The average evaluation score on the question "How valuable did you find the conference overall?" was 4.66 on a 5-point scale.
- Existing and new members enjoyed networking during the Welcome Dinner, coffee breaks, between sessions, and during the poster sessions.

• Writing Groups were formulated and started brainstorming on the topics listed in the Writing Group Update below.



## Writing Group Update

During the 2017 Network meeting, attendees had the opportunity to sign-up to participate in writing group topics. The Steering Committee was thrilled to see that there was great interest in participating in the writing groups. If any member is interested in participating in one of the writing groups listed below, or would like to suggest an additional topic, please email the Network Executive Office (<u>info@cancersexnetwork.org</u>).

## Writing Groups:

- Health behaviors and sexual function among female cancer patients
- Communication in the area of sexual health and cancer patients
- Self-help: Qualitative survey of what cancer patients have tried
- Partner's perspective of their own sexual function in correspondence with the cancer patient's own rating
- Sexual function, cancer, and other co-morbid conditions
- The impact of non-chemotherapeutic medications on sexual function
- Professional training/education in specific fields

## Update from the Communication in the Area of Sexual Health and Cancer Patients Writing Group:

The Communication Writing Group held its first conference call on Thursday, May 25, with eight attendees. The members of this group span a range of disciplines, including clinical psychology, nursing, gynecology, social work, and sex therapy. The major goal of this working group will be to develop and publish one or more scientific manuscripts aimed at moving the field forward in the area of patient-provider communication about sexual health for women with cancer. Specific paper topics and areas of potential focus were discussed, including 1) patient self-efficacy and activation, 2) paradigm shift: barriers and facilitators, 3) sexual communication with intimate partners and 4) review of psychosocial factors/barriers (e.g. age, gender) contributing to patterns of patient-provider communication. Next steps involve narrowing paper topic or topics, considering method, identifying lead authors, and clarifying participant roles per project(s).

## **Membership Committee Update**

The Membership Committee is focused on inviting potential members to join the Network. We are excited to welcome the 15 new members who have joined since March! We encourage you to refer friends and colleagues who are also committed to our mission and vision to join us in our efforts! The Membership Committee is developing a plan to expand the Network's presence through social media, as well as involving new members in the initiatives of the Network, such as the writing groups.

### Welcome New Members!

- Lisa Anllo, PhD, Buffalo, NY
- Hui (Amy) Chen, MD, Sacramento, CA (UC Davis)
- Jessica Fox, MS, Plantation, FL (Nova Southeastern University
- Eugenia (Jane) Girda, MD, Sacramento, CA (UC Davis)
- Jessica Gorman, PhD, MPH, Corvallis, OR (Oregon State University)
- Dana Haseotes, MSW, LICSW, MPH, CST, North Attleboro, MA (Brown University)
- Heather Howard, PhD, MPH, San Francisco, CA (Center for Sexual Health and Rehabilitation)
- Cheryl Hysjulin, RN, PsyD, Fargo, ND (Roger Maris Cancer Center Sanford Health)
- Usha Menon, PhD, RN, FAAN, Tuscon, AZ (University of Arizona)
- Allison Quick, MD, Columbus, OH (Ohio State University)
- Amanda Shepherd, MD, Sacramento, CA (UC Davis)
- Brett Smith-Hams, MD/MPH Candidate, Los Altos, CA (St. George's University School of Medicine)
- Christiana von Hippel, Cambridge, MA (Dana Farber Cancer Institute)
- Sarah Watson, MD, Sacramento, CA (UC Davis)
- Alicia Young, MS, Ft. Lauderdale, FL (Nova Southeastern University)

# Spotlight on Research

#### Assessment of Vulvar Discomfort with Sexual Activity Among Women in the United States

In an effort to improve the measurement of patient-reported health, the NIH funded the creation of PROMIS (Patient Reported Outcomes Measurement Information System), which included development of the PROMIS Sexual Function and Satisfaction measure. Version 2.0 of the Sexual Function and Satisfaction measure included two scales to measure vulvar discomfort and sexual activity.

A number of Network members were involved in a study to describe the development of two self-reported measures of vulvar discomfort with sexual activity, to describe the relationships between these scales and scales for lubrication and vaginal discomfort, and to report the prevalence of vulvar discomfort with sexual activity in a large, national representative sample of US women. The study was published in the April 2017 issue of the American Journal of Obstetrics & Gynecology.

The study found that there was limited overlap between the vulvar discomfort domains and the domains of vaginal lubrication and vaginal discomfort during sexual activity, which shows that these PROMIS measures of vulvar discomfort provide further insight about sexual function. Future studies should further research the effects of diseases and their treatments on vulvar discomfort with sexual activity as well as evaluate interventions to mitigate vulvar discomfort.

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