

# Urology Update

SPECIAL EDITION

## Prostate Cancer Consensus 2017

### The Role of Genetic Testing for Inherited Prostate Cancer Risk

The field of genetic testing is evolving rapidly, and men diagnosed with prostate cancer often ask about the implications of their diagnosis on their children and other relatives. To bring clarity and understanding to providers and their patients on the best approaches to genetic testing and referral guidelines for prostate cancer patients and their relatives, the Sidney Kimmel Cancer Center and the Foundation for Breast and Prostate Health co-sponsored the first international Prostate Cancer Consensus 2017 to address the “Role of Genetic Testing for Inherited Prostate Cancer Risk.”

The purpose of the Consensus (held March 3,4 on the Jefferson Campus) was to provide guidance to providers and patients based on the latest information on what are the genetics of prostate cancer, who should be referred for genetic counseling, and which genes may have the greatest impact for prostate cancer patients and their families. Issues surrounding genetic counseling were also addressed, such as considerations for panel testing, reproductive implications, cost issues and genetic discrimination laws. Molecular



Keynote speaker Mr. Robin Cole (left) with Consensus Co-chairs Drs. Karen Knudsen, Veda Giri and Leonard Gomella.



Consensus participants.



Drs. Hamdy (Oxford University, England), Bangma (Erasmus University, the Netherlands) with Drs. Trabulsi, Mann and Hubosky.





6 ABC News TV coverage.



More than 60 content experts participated in the two-day Consensus in March.



Dr. Tricia Gomella's Consensus Mascot and AT-GC treats.



Dr. Giri and Gomella welcoming participants.



Consensus expert panel members group photo.



Keynote Speaker/Advocate Robin Cole, Two-time Super Bowl Champion.



Panel members discussing critical genetic testing issues.



Panel members represented a dozen areas of expertise.



Patient advocates with retired Pittsburgh Steeler Robin Cole (center).

and genomic tumor analysis were also briefly addressed in the context of evaluation for prostate cancer inheritance.

More than 60 experts and stakeholders from the United States, Canada, Great Britain and the Netherlands discussed, debated and defined "The Role of Genetic Testing for Inherited Prostate Cancer Risk." Since the issue of genetic testing involves inherited risk for prostate cancer and encompasses risks for other cancers affecting both males and females, the panel discussions and keynote presentation helped frame the real-world applications of prostate cancer genetic testing.

The Consensus assembled a group of panel members and faculty prostate cancer experts, including urologists, medical oncologists, radiation oncologists, clinical cancer genetics experts, pathologists, gynecologists, primary care providers, community urologists, genetic counselors, social workers, bioethicists, basic science researchers and patient advocates.

Leonard G. Gomella, MD, Karen Knudsen, PhD, and Veda Giri, MD,\* served as Consensus co-chairs. More than a dozen other Jefferson faculty were engaged as members of the steering committee or as a panel member. This steering committee was co-chaired by Drs. Kevin Kelly, Stephen Peiper and Gordon Schwartz.

Mr. Robin Cole, retired Pittsburgh Steeler, two-time Super Bowl champion and founder of the OBEDIAH Foundation, was the keynote speaker. His address, "A Patient's Perspective on Familial Prostate Cancer Risk Assessment," focused on his personal challenges and those faced by his father and brothers due to familial prostate cancer.

Discussions centered on developing genetic referral guidelines for prostate cancer patients and their blood relatives and the relationship between inherited diseases such as breast, ovarian and other cancers and the current understanding of how these related tumors guide

prostate cancer genetic testing. Additionally, the elements of genetic counseling were outlined, as well as the genes to test in the context of inherited prostate cancer risk. The potential role of genetic testing in prostate cancer management and the current role in screening for prostate cancer were also part of the discussions.

Questions addressed that as the number of relatives with prostate cancer increases, so does a man's lifetime risk of the disease. What is increasingly recognized is that other familial malignancies such as breast, ovarian, colon, pancreatic, endometrial cancers and melanoma may be connected to inherited risk for prostate cancer in a family due to common genetic mutations accounting for hereditary cancer syndromes. Identifying men who may be at risk for inherited prostate cancer and genetically related malignancies would allow directed attempts at early diagnosis and potential prevention strategies for prostate and other cancers. Advances in genetic testing for inherited and familial prostate cancer were determined to be necessary to inform personalized cancer risk screening and treatment approaches.

Furthermore, genetic information may also provide individualized estimates of disease prognosis and severity in order to tailor management

The ultimate goal of the conference is to publish consensus guidelines for genetic testing for inherited prostate cancer risk to guide patients and providers with this decision in the rapidly evolving genetic era. A major journal paper will be generated with additional plans for national and international meeting presentations.

Prostate cancer, a major healthcare burden in the United States and in most other western countries, is the leading solid tumor in American men and a major cause of morbidity and mortality. Since prostate cancer is both a clinically and genetically heterogeneous disease, it is estimated that inherited factors may account for up to 40-50% of cases likely from a combination of rare, high-penetrance gene mutations, as well as common variants. The current understanding is that approximately 5-10% of inherited prostate cancer is due to more commonly identified important genes conferring a significantly increased lifetime risk for the disease.

\* Dr. Gomella, The Bernard W. Godwin Jr. Professor of Prostate Cancer; Chairman, Department of Urology; Senior Director Clinical Affairs, Sidney Kimmel Cancer Center; Clinical Director, Jefferson Sidney Kimmel Cancer Network  
Dr. Veda N. Giri, Director, Cancer Risk Assessment and Clinical Cancer Genetics; Associate Professor, Department of Medical Oncology  
Dr. Karen E. Knudsen, Director of Sidney Kimmel Cancer Center; The Hilary Koprowski Professor and Chair of Cancer Biology





Shelley Schwartz, Founder of the Foundation for Breast and Prostate Health, opening remarks.



Fox 29 TV Interview with Dr. Gomella and Mr. Cole on the Consensus.



Panel members enjoying A Taste of Philly Luncheon.



SKMC Dean Mark Tykocinski welcomed the group to Jefferson.

## SESSION TOPICS

### SESSION I: INTRODUCTION AND OVERVIEW

- Why is this Consensus is needed in 2017?
- Consensus program and process to be followed
- Endorsements
- The Burden of Prostate Cancer Today and in the Future
- A Patient's Perspective on Familial Prostate Cancer Risk Assessment

### SESSION II: OVERVIEW OF CONTEMPORARY GENETIC COUNSELING

- Summary of current genetic testing capabilities and recommendations for inherited cancer risk assessment
- Overview of the principles of genetic testing and genetic counseling
- Models of Genetic Testing in Other Cancers

### SESSION III: PRACTICAL CONSIDERATIONS OF GENETIC TESTING AND COUNSELING

- Ethical considerations in testing for inherited diseases
- Financial considerations in genetic testing
- What is the role of primary care and other providers in genetic testing for inherited cancer risk?

### SESSION IV: PROSTATE CANCER GENOMICS AND GENETICS

- Emerging insights into the genetic contribution to prostate cancer risk (Part 1)

### SESSION V: PROSTATE CANCER GENOMICS AND GENETICS (CONTINUED)

- Emerging insights into the genetic contribution to prostate cancer risk (Part 2 continued)
- Additional genomic approaches

### SESSION VI: CLINICAL APPLICATIONS OF PROSTATE CANCER GENOMICS AND GENETICS

- Is there a role for genetic testing in prostate cancer screening strategies?
- Current and future role of genetic testing in the management of prostate cancer
- Specific Populations to Consider For Genetic Testing For Prostate Cancer Predisposition

### SESSION VII: REVIEW OF PROSTATE CANCER GENETIC CLINICAL TRIALS

- Ongoing and completed relevant prostate cancer genetic clinical trials

### SESSION VIII: CONSENSUS TOPICS FOR DELIBERATION

- Deliberations being used to determine the content of the final consensus paper

# Panel Members

| Panel Member/Specialty  | Institution  | Panel Member/Specialty                              | Institution  |
|---|--|---|--|
| Wasim Abida, MD, PhD/Medical Oncology   | Memorial Sloan Kettering Cancer Center   | Peter McCue, MD/Pathology                           | Jefferson Sidney Kimmel Cancer Center  |
| Chris Bangma, MD, PhD/Urology   | Erasmus Medical Center, Rotterdam, The Netherlands   | Martin Miner, MD/Primary Care                       | Brown University   |
| Mitchell Benson, MD/Urology   | Columbia University  | Todd Morgan, MD/Urology                             | University of Michigan   |
| Amie Blanco/Genetic Counseling  | UCSF Helen Diller Family Comprehensive Cancer Center   | Judd Moul, MD/Urology                               | Duke University, Duke Cancer Institute   |
| John Buehler/Patient Advocate   | N/A  | Ron Myers, PhD/Medical Decision Making Research     | Jefferson Sidney Kimmel Cancer Center  |
| Arthur "Bud" Burnett, MD, MBA/Urology   | Johns Hopkins Medical Institutions   | Sarah Nielsen, MS, CGC/Genetic Counseling           | The University of Chicago  |
| William Catalona, MD/Urology  | Northwestern University, Feinberg School of Medicine; R.H. Lurie Comprehensive Cancer Center | Elias Obeid, MD, MPH/Medical Oncology               | Fox Chase Cancer Center  |
| Robin Cole/Patient Advocate   | N/A  | Christian Pavlovich, MD/Urology                     | Johns Hopkins Medical Institutions   |
| Kathleen Cooney, MD/Medical Oncology/Genetics   | University of Utah School of Medicine  | Stephen Peiper, MD/Pathology                        | Jefferson Sidney Kimmel Cancer Center  |
| Matthew Cooperberg, MD, MPH/Urology   | UCSF Helen Diller Family Comprehensive Cancer Center   | David Penson, MD, MPH/Urology                       | Vanderbilt University Medical Center   |
| David Crawford, MD/Urology  | University of Colorado, Denver   | Daniel Petrylak, MD/Med Oncology                    | Yale University  |
| Robert Den, MD/Radiation Oncology   | Jefferson Sidney Kimmel Cancer Center  | Curtis Pettaway, MD/Urology                         | MD Anderson Cancer Center  |
| Adam Dicker, MD, PhD/Radiation Oncology   | Jefferson Sidney Kimmel Cancer Center  | Robert Pilarski, MS, LGC, MSW/Genetic Counseling    | The Ohio State University  |
| Scott Eggener, MD/Urology   | University of Chicago  | Peter Pinto, MD/Urology                             | National Cancer Institute  |
| Neil Fleshner, MD/Urology   | University of Toronto, Princess Margaret Cancer Centre                                       | Wendy Poage, MHA/Prostate Cancer Education/Advocacy | Prostate Condition Educ Council  |
| Matthew L. Freedman, MD/Medical Oncology/Genetics   | Harvard Medical School/Dana-Farber Cancer Institute  | Ganesh Raj, MD, PhD/Urology                         | University of Texas Southwestern Medical Center at Dallas                                    |
| Veda Giri, MD/Medical Oncology/Genetics   | Jefferson Sidney Kimmel Cancer Center  | Tim Rebbeck, PhD/Genetic Research                   | Harvard/Dana Farber Cancer Institute   |
| Leonard G. Gomella, MD/Urology  | Jefferson Sidney Kimmel Cancer Center  | Mark Robson, MD/Breast Oncology/Genetics            | Memorial Sloan Kettering Cancer Center   |
| Freddie Hamdy, MBChB, LRCSPEd, LRCSEd, LRCPSGlas, FRCSEd, MD, FRCSEd(Urol), MA (Oxon), FRCS, FMedSci./Urology | University of Oxford, Oxford, England  | Matt Rosenberg, MD/Primary Care                     | Mid Michigan Health Center   |
| Jean Hoffman-Censits, MD/Medical Oncology   | Jefferson Sidney Kimmel Cancer Center  | Howard Sandler, MD/Radiation Oncology               | Cedars-Sinai Medical Center  |
| Mark Hurwitz, MD/Radiation Oncology   | Jefferson Sidney Kimmel Cancer Center  | Oliver Sartor, MD/Medical Oncology                  | Tulane University Medical School   |
| William Isaacs, PhD/Genetics Research   | Johns Hopkins Medical Institutions   | Edward "Ted" Schaeffer, MD, PhD/Urology             | Northwestern University, Feinberg School of Medicine; R.H. Lurie Comprehensive Cancer Center |
| Christopher Kane, MD/Urology  | University of California San Diego   | Gordon Schwartz, MD/Breast Surgery                  | Foundation for Breast & Prostate Health  |
| Philip Kantoff, MD/Medical Oncology   | Memorial Sloan Kettering Cancer Center   | Mark Shahin, MD/Gynecologic Oncology                | Hanjani Institute for Gynecologic Oncology; Abington Hospital-Jefferson Health               |
| R. Jeffrey Karnes, MD/Urology   | Mayo Clinic, Rochester   | Neal Shore, MD/Urology                              | Atlantic Urology Clinics/CURC  |
| Larry Karsh, MD/Urology   | The Urology Center of Colorado   | Brian Shuch, MD/Urology                             | Yale University  |
| Peter Kaye, Sr./Patient Advocate  | N/A  | Howard Soule, PhD/Basic & Clinical Research         | Prostate Cancer Foundation   |
| Kevin Kelly, DO/Medical Oncology  | Jefferson Sidney Kimmel Cancer Center  | Scott Tomlins, MD, PhD/Pathology                    | University of Michigan Medical School  |
| Eric Klein, MD/Urology  | Cleveland Clinic   | Edouard J. Trabulsi, MD/Urology                     | Jefferson Sidney Kimmel Cancer Center  |
| Karen Knudsen, PhD/Oncology Research  | Jefferson Sidney Kimmel Cancer Center  | Robert Uzzo, MD/Urology                             | Fox Chase Cancer Center  |
| Daniel Lin, MD/Urology  | University of Washington   | Donald J. Vander Griend, PhD/Genetic Counseling     | The University of Chicago  |
| Kevin Loughlin, MD, MBA/Urology   | Brigham & Women's Hospital, Harvard Medical School   | Patrick C. Walsh, MD/Urology                        | Johns Hopkins Medical Institutions   |
| Grace LuYao, PhD/Population Science   | Jefferson Sidney Kimmel Cancer Center  | Carol Weil, JD/Bioethics                            | National Cancer Institute  |
| S. Bruce Malkowicz, MD/Urology  | University of Pennsylvania   | Richard Wender, MD/Family & Community Medicine      | American Cancer Society  |
| Mark Mann, MD/Urology   | Jefferson Sidney Kimmel Cancer Center  |   |  |
| J. Ryan Mark, MD/Urology  | Jefferson Sidney Kimmel Cancer Center  |   |  |

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