



Informed Prostate Cancer Support Group Inc.

"A 501 C 3 CORPORATION ID # 54-2141691"



Saturday, August 17, 2024

AUGUST 2024 NEWSLETTER

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Volume 17 Issue 08

Next IPCSG Meeting **3rd Saturday,** **10am August 17, 2024**

- **Telix - Future of Precision Medicine for Prostate Cancer**
- Denise Guilbault from Telix pharmaceuticals will give a presentation on their new Lutetium based therapy and their current diagnostic tools. Telix, based in Australia, is a commercial-stage biopharmaceutical company focused on the development and commercialization of therapeutic and diagnostic ('theranostic') radiopharmaceuticals. For more information, visit their website: <https://telixpharma.com/>
- There will be a light lunch provided after the meeting
- For links to further Reading: <https://ipcsfg.blogspot.com/>
- If you have Comments, Ideas or Questions, email to Newsletter@ipcsfg.org
- **For more information, please send email to bill@ipcsfg.org or call Bill at (619) 591-8670**

Informed Prostate Cancer Support Group July 20, 2024

Member Roundtable Discussion - YouTube Round Table Discussion

Meeting Summary

Overall Summary:

This July 20th meeting of a prostate cancer support group was the first in person meeting of the IPCSG in the newly refurbished Sanford Burnham Prebys Medical Exploration Auditorium. The session included presentations from three speakers who shared their personal experiences with prostate cancer, treatment approaches, and insights into managing the disease. The meeting also addressed the importance of self-advocacy, staying informed, and maintaining a positive outlook while dealing with prostate cancer.

Contributions:

1. Bill Manning:

Bill shared his journey with active surveillance over 15 years. He emphasized the importance of regular testing and monitoring, including PSA tests, MRIs, and biopsies. Bill discussed how he avoided unnecessary treatment by carefully tracking his condition and making informed decisions. He also highlighted the potential benefits of dietary changes, particularly adopting a vegan diet based on "The China Study."

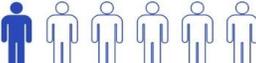
2. Mike McCary:

Mike presented his seven-year journey with prostate cancer, focusing on an integrative approach combining

(Continued on page 3)

Prostate Cancer: GET THE FACTS

Other than skin cancer, prostate cancer is the most common cancer in American men.

1 in 6 
men will be diagnosed with prostate cancer during his lifetime.



Prostate cancer can be a serious disease, but most men diagnosed with prostate cancer do not die from it. In fact, more than 2.5 million men in the United States who have been diagnosed with prostate cancer at some point are still alive today.

Organization

a 501c3 non-profit organization - all positions are performed gratis



Officers

Bill Lewis President
Stephen Pendergast—Secretary

Additional Directors

Gene Van Vleet
Aaron Lamb
Bill Manning

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Bill Bailey, Librarian
Mike Corless, Greeter
Aaron Lamb, Meeting Set-up
Stephen Pendergast Editor

NEWSLETTER

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PROSTATE CANCER—2 WORDS, NOT A SENTENCE

What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PCa are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

Join the IPCSG TEAM

If you consider the IPCSG to be valuable in your cancer journey, realize that we need people to step up and HELP. Call **President Bill Lewis @ (619) 591-8670** "bill@ipcs.org"; or **Director Gene Van Vleet @ 619-890-8447.**

From the Editor (SVP)

In this issue:

For original articles see the blog at <https://ipcs.blogspot.com/> . First, we have a claude.AI generated summary of the latest July member roundtable meeting. There were many insights to be gained from these talks.

This month, we include several items of interest:

1. Burden of 30 cancers among men: Global statistics in 2022 and projections for 2050 using population-based estimates - Bizuayehu - Cancer - Wiley Online Library—*Statistics for Prostate Cancer extracted—global prognosis is grim*
2. Cardiovascular risks of androgen receptor targeted agents in prostate cancer: a systematic review and meta-analysis “PCAN-23-0763R” - *some of the new add on ARTA drugs for ADT carry substantial cardiac risk*
3. Salvage treatments after focal therapy for prostate cancer – a comprehensive review | Prostate Cancer and Prostatic Diseases—if spot treatment for localized PC fails, salvage treatments can still work.

(Continued from page 1)

Western and alternative medicine. He discussed his treatment history, including surgery and radiation, and shared his experiences with various supplements and lifestyle changes. Mike emphasized the importance of research, stress management, and emotional well-being. He provided practical tips for coping with the psychological aspects of cancer, such as visualization techniques and the "60-second rule" for managing negative thoughts.

3. Herschel Kagan:

Herschel shared his experience with more advanced prostate cancer, including his diagnosis and treatment with hormone therapy and radiation. He discussed his decision to switch medications and his goal of eventually stopping hormone treatment. Herschel also provided insight into the U.S. Preventive Services Task Force's recommendations regarding PSA testing and how these recommendations may have impacted his diagnosis. He raised important questions about the balance between over-diagnosis and catching cancer early.

The meeting concluded with a Q&A session where attendees could ask the speakers questions about their experiences and approaches to managing prostate cancer. The overall message emphasized the importance of being proactive, well-informed, and maintaining a positive attitude while dealing with prostate cancer.

Summary by Speaker Segment

Welcome and Introduction by Aaron Lamb

During this segment, Aaron Lamb, director and facilitator of the meetings, welcomes everyone to the members' roundtable discussion. He introduces the key people involved in the organization, including Bill Lewis, Gene van Vleet, Steve Pendergast, Bill Manning, and himself. Aaron mentions that the meeting is recorded and available on YouTube, and invites newcomers to fill out a profile form to receive information and support. He also mentions the organization's social media presence and various resources available, including PSA testing, gene-based testing, and exercise programs. Additionally, Aaron apologizes for canceling the previous meeting and invites volunteers to help with various tasks, such as meeting facilitation, newsletter editing, and accounting assistance, highlighting the importance of teamwork and support within the organization.

Bill Manning

Patient Empowerment through Knowledge Sharing

The selected segment discusses the importance of patient empowerment through knowledge sharing, specifically in the context of prostate cancer treatment. The speaker, Bill Manning, shares his personal experience with active surveillance and the importance of seeking multiple opinions when navigating treatment options. He highlights the role of support groups, such as IP CSG, in providing educational resources and emotional support to patients. Bill also emphasizes the need for patients to be proactive in their healthcare, advocating for themselves, and seeking out alternative treatment options, including Western and alternative medicine approaches.

Low-Risk Prostate Cancer Management through Active Surveillance

The speaker shares his personal experience with low-risk prostate cancer, undergoing active surveillance for 15 years. He highlights the importance of PSA density score, which is a ratio of prostate gland volume to PSA score. The speaker emphasizes the need for patient empowerment and informed decision-making in prostate cancer treatment. He also discusses the challenges of overdiagnosis and overtreatment and urges attendees to be proactive in their healthcare and seek multiple opinions to make informed choices. Additionally, he explains the role of support groups in providing emotional and educational resources, emphasizing the need for patient advocacy and a positive outlook in navigating this journey.

Mike McCarey

Importance of Prostate Cancer Testing and Treatment Options

The speakers discussed the importance of getting a PSA test if you experience symptoms that lead you to visit a urologist, and the importance of getting an MRI before undergoing a biopsy. They also emphasized the need for patient education and empowerment, highlighting the role of support groups in providing emotional and educational resources. The speakers shared their personal experiences with prostate cancer treatment, including using integrative approaches that combine Western medicine and alternative medicine.

Empowerment Through Informed Decision-Making and Holistic Approach

The speaker shares his personal experience with prostate cancer treatment, emphasizing the importance of

(Continued on page 4)

being an active advocate in one's healthcare. He discusses how seeking multiple opinions and remaining open to alternative approaches, such as sSRT radiation and bio care hospital's alternative medicine programs, helped him make informed decisions and achieve the best possible outcomes. The speaker also highlights the importance of being proactive, seeking second opinions, and considering the benefits of both Western and alternative medicine approaches in navigating the complex and often uncertain journey of prostate cancer treatment.

Emotional Survival and Stress Reduction Techniques

In this segment, the speaker shares his personal experiences and strategies for emotional survival and stress reduction while living with prostate cancer. He emphasizes the importance of being proactive in one's healthcare, educating oneself about treatment options, and seeking multiple opinions to make informed decisions. He also discusses the benefits of journaling and keeping a "cancer resources" document, which can help individuals keep track of their medical history, test results, and treatment plans. Additionally, he shares five emotional tips to reduce stress, including being positive, rearranging one's thinking, eliminating stress, visualization, and controlling the "dark place" by processing negative thoughts and emotions.

Herschel Kagan

Prostate Cancer Diagnosis and Treatment: A Personal Journey

The speaker shares his personal experience with prostate cancer, from being diagnosed with BPH to being referred to a urologist and eventually undergoing a biopsy and receiving a Gleason score of 4+5. He discusses his treatment journey, including radiation therapy and hormone-suppressing drugs. The speaker also expresses his concerns about the limitations of the US Preventive Services Task Force recommendations for PSA testing and the risks of overdiagnosis and overtreatment.

Q&A Discussion

Prostate Cancer Screening and Treatment: The Role of PSA Testing and Patient Empowerment

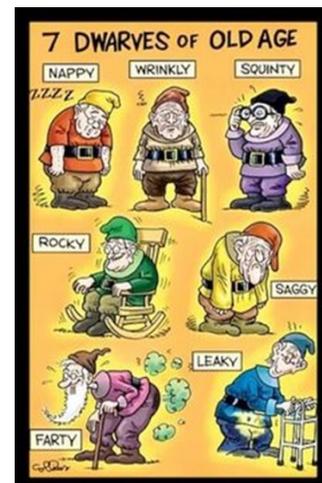
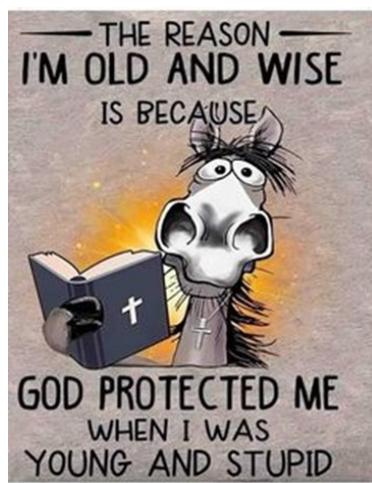
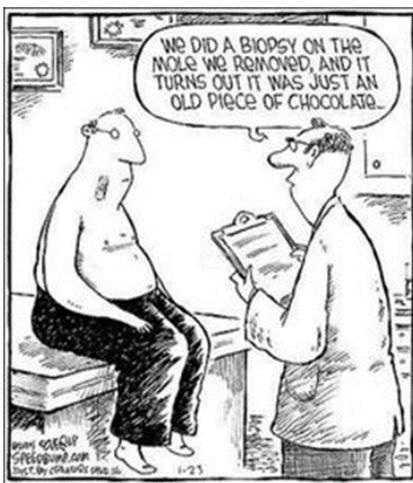
The discussion highlights the complexities of prostate cancer screening and treatment, particularly the role of PSA testing. Bill Manning shares his personal experience with active surveillance and how his PSA score changed over time, emphasizing the need to consider patient preferences and professional judgment. The conversation also touches on the challenges of overdiagnosis and overtreatment, and the importance of integrating Western and alternative medicine approaches.

Supplements and Sleep Management

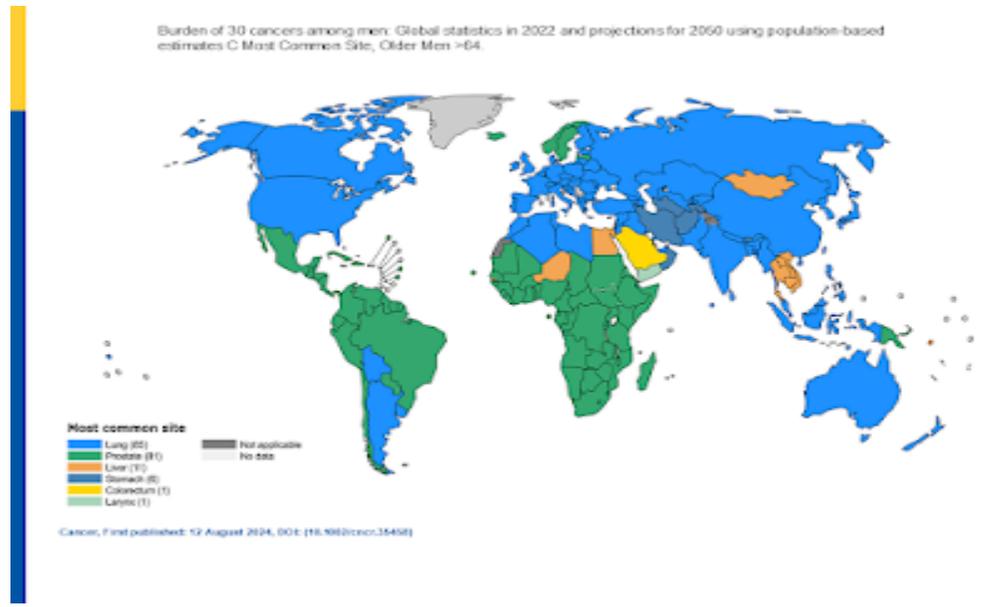
The speaker discusses the importance of sleep management and recommends certain supplements such as ap-
pine, l-theanine, and magnesium glycinate to help relax and improve sleep. He also shares his personal experience with sleep and how he uses cannabis-based products to aid in sleep. The speaker emphasizes the importance of experimenting with different approaches to find what works best for individual needs.

Video of meeting and edited transcript is available at <https://ipscg.blogspot.com/2024/08/member-roundtable-discussion-youtube.html>

On The Lighter Side



Items of Interest



Geographical Distribution of Most Prevalent Cancer among Men >64 -
Prostate Cancer leads in Latin and South America, Africa, Scandinavia

Burden of 30 cancers among men: Global statistics in 2022 and projections for 2050 using population-based estimates - Bizuayehu - Cancer - Wiley Online Library

[Habtam Mellie Bizuayehu PhD](#), [Abel F. Dadi PhD](#), [Kedir Y. Ahmed PhD](#), [Teketo Kassaw Tegegne PhD](#), [Tahir Ahmed Hassen PhD](#), [Getiye Dejen Kibret PhD](#), [Daniel Bekele Ketema MPH](#) ... [See all authors](#)

First published: 12 August 2024

<https://doi.org/10.1002/cncr.35458>

Summary for Prostate Cancer Projections and Statistics

Based on the article, we've extracted the key points about prostate cancer projections and statistics:

In 2022, prostate cancer was:

The leading cancer type in terms of cases in about two-thirds (117) of the 185 countries/territories studied.

The second most common cancer type overall in terms of age-standardized incidence rate (29.4 per 100,000 men).

The fifth leading cause of cancer deaths in terms of age-standardized mortality rate (7.3 per 100,000 men).

Projections for 2050:

Prostate cancer deaths are projected to increase by 136.4% between 2022 and 2050, which is the highest projected increase in deaths among all cancer types.

The number of prostate cancer cases is expected to increase from 1,467,854 in 2022 to 2,879,501 in 2050, a 96.2% increase.

Deaths are projected to increase from 397,430 in 2022 to 939,534 in 2050.

Age-specific statistics (2022):

Among older adults (65 years and older), prostate cancer had the highest age-standardized incidence rate (291.4 per 100,000 men).

For the working-age group (15-64 years), prostate cancer was the third most common cancer in terms of incidence.

Mortality-to-incidence ratio (MIR):

The overall MIR for prostate cancer was 24.8%, indicating a relatively lower mortality rate compared to its incidence rate.

This MIR was lower than many other cancer types, suggesting better survival rates for prostate cancer compared to some other cancers.

Geographic variations:

Prostate cancer was the leading cancer type in terms of cases in 139 out of 185 countries/territories among older adults.

There were significant variations in prostate cancer burden across different Human Development Index (HDI) levels and World Health Organization regions, though specific details for prostate cancer were not provided.

The article emphasizes the need for male-specific cancer screening programs, as there are currently no well-adapted screening programs for prostate cancer comparable to those for female-specific cancers like breast and cervical cancer.

Rationale

The article provides several rationales for the cancer projections, including those for prostate cancer. Here are the key points:

Demographic changes: The projections take into account population growth and aging. The article notes that cancer cases and deaths are expected to increase more significantly among older adults (65 years and older) compared to younger age groups. Since prostate cancer is more common in older men, this demographic shift likely contributes to its projected increase.

Calculation method: The projections for 2050 were derived through demographic projections, assuming that the 2022 estimated rates remain constant. They calculated projections every 5 years by multiplying the 2022 age-specific rates with corresponding population projections for the target years.

Development status: The article notes that cancer burden is expected to increase more rapidly in countries with lower Human Development Index (HDI) scores. This suggests that as these countries develop and life expectancy increases, they may see a rise in cancers that are more common in older populations, like prostate cancer.

Lack of male-specific screening programs: The article mentions that unlike female-specific cancers (breast and

(Continued from page 6)

cervical), there are no comparable screening programs for male-specific cancers like prostate cancer. This lack of screening could contribute to later-stage diagnoses and potentially higher mortality rates in the future.

Modifiable risk factors: The article discusses how men exhibit higher prevalence of modifiable risk factors, such as smoking and alcohol consumption. While not specific to prostate cancer, these factors could influence overall cancer trends.

Health system preparedness: The projections highlight the need for health systems to prepare for a significant increase in cancer burden, including prostate cancer cases and deaths.

Data quality considerations: The authors acknowledge that the quality of data varies between countries, which could affect the accuracy of both current estimates and future projections, especially in low and medium HDI countries.

It's important to note that these projections assume current rates remain constant and do not account for potential future changes in prevention, screening, or treatment technologies that could significantly alter the trajectory of prostate cancer incidence and mortality.

Cardiovascular risks of androgen receptor targeted agents in prostate cancer: a systematic review and meta-analysis “PCAN-23-0763R” | Prostate Cancer and Prostatic Diseases

[nature.com](https://www.nature.com)

Fitzgerald, B.

Summary

The standard of care for Prostate Cancer in older men has been until recently Androgen Deprivation Therapy (ADT) in combination with surgery or radiation. With recurrence, ADT can go on for an extended period combined with ARTA agents, leading to examination of the cardiac risks associated with this therapy. The androgen receptor targeted agents (ARTA) typically used in prostate cancer treatment include:

1. Abiraterone
2. Enzalutamide
3. Apalutamide
4. Darolutamide
5. Orteronel

The article mentions that these were the ARTA agents used in the studies included in the systematic review and meta-analysis conducted by Ong et al. It's worth noting that these agents are often used in combination with androgen deprivation therapy (ADT) for the treatment of metastatic prostate cancer.

The article also points out that in many countries, including the author's, the use of an ARTA in combination with either an LHRH (luteinizing hormone-releasing hormone) agonist or antagonist has received Medicare funding for patients with metastatic prostate cancer. This is due to the observed benefits in long-term prostate cancer-specific survival and freedom from progressive disease.

Each of these agents may have different risk profiles and efficacy, but the article suggests that more research is needed to definitively determine which ARTA might be safest in terms of cardiac risk.

This article is a commentary on a systematic review and meta-analysis conducted by Ong et al. regarding the cardiovascular risks associated with androgen receptor targeted agents (ARTA) in prostate cancer treatment. Here are the key points:

(Continued on page 8)

1. The meta-analysis found that using ARTA in prostate cancer treatment increases the incidence of cardiac-related adverse events.
2. Specific findings include:
 - 69% increased risk of hypertension
 - 143% increased risk of hypertensive crisis
 - 84% increased risk of ischemic heart disease events
 - 38% increased risk of arrhythmia
3. Despite these increased risks, ARTA did not significantly increase the incidence of cardiac arrests or deaths.
4. The authors note that the mechanisms of interaction between hormonal agents and the cardiovascular system are complex and multifaceted.
5. The commentary highlights the need for cardiac assessment before starting ARTA treatment, especially for patients with known cardiac history.
6. It's noted that real-world data may differ from clinical trials due to more restrictive selection criteria in trials.
7. The article concludes by emphasizing the need for more research to identify at-risk groups and provide better guidance for clinicians on managing cardiovascular risks in prostate cancer patients treated with ARTA.
8. The commentary also mentions that the meta-analysis couldn't provide robust information about which ARTA is safest in terms of cardiac risk, due to limited studies and the novelty of some drugs.

This summary provides an overview of the key findings and implications discussed in the article regarding the cardiovascular risks associated with ARTA in prostate cancer treatment.

Q&A

As a patient undergoing ARTA treatment for metastatic prostate cancer, you should consider asking your oncologist the following questions:

1. What is my individual cardiovascular risk profile?

Expected answer: Your oncologist should discuss your personal risk factors, including age, existing cardiac conditions, blood pressure, cholesterol levels, and other relevant medical history.

2. Should I undergo a cardiac assessment before starting ARTA treatment?

Expected answer: Based on the article, your oncologist might recommend a baseline cardiovascular risk assessment, especially if you have a known cardiac history or risk factors.

3. Which ARTA are you recommending for me, and why?

Expected answer: Your oncologist should explain the choice of specific ARTA (e.g., abiraterone, enzalutamide) based on your cancer characteristics and overall health status.

4. What cardiac-related side effects should I watch for during treatment?

Expected answer: They should mention potential symptoms of hypertension, ischemic heart disease, and arrhythmias, providing specific signs to be aware of.

5. How will my cardiac health be monitored during treatment?

Expected answer: Your oncologist should outline a plan for regular monitoring, which may include blood pressure checks and periodic cardiac evaluations.

6. Should I see a cardiologist before or during my ARTA treatment?

Expected answer: If you have existing cardiac issues or significant risk factors, your oncologist might recommend a cardiology consultation.

Regarding coordination of care:

1. Multidisciplinary approach: Your prostate cancer therapy should ideally be coordinated among your oncologist, urologist, cardiologist (if needed), and primary care physician. This ensures comprehensive care that addresses both your cancer treatment and overall health.

2. Shared decision-making: Treatment decisions should involve input from all relevant specialists. For example, your cardiologist might provide recommendations on managing cardiovascular risks while undergoing ARTA treatment.

3. Regular communication: Ensure there's a system in place for your various healthcare providers to communicate about your treatment progress and any emerging issues.

4. Proactive management: Your care team should work together to optimize your cardiovascular health before and during ARTA treatment. This might involve adjusting medications, lifestyle modifications, or closer monitoring.

5. Patient-centered care: You should be kept informed and involved in all decisions, with clear explanations of the risks and benefits of different treatment options.

6. Follow-up plan: There should be a clear plan for follow-up appointments with all relevant specialists to monitor both your cancer progression and overall health status.

Remember, the goal is to balance effective cancer treatment with maintaining your overall health and quality of life. Don't hesitate to ask for clarification or express any concerns to your healthcare team.

Salvage treatments after focal therapy for prostate cancer – a comprehensive review | Prostate Cancer and Prostatic Diseases

[nature prostate cancer and prostatic diseases review articles](#) Published: 01 August 2024
Lorenzo Storino Ramacciotti, Andre Luis Abreu, Sébastien Crouzet, Petr Macek, Brian J. Miles, Rahim Horuz, Diogo Nunes-Carneiro, Phillip Stricker, Stephen Scionti & M. Pilar Laguna

[Prostate Cancer and Prostatic Diseases \(2024\)](#) [Cite this article](#)

Abstract

Objective

To review the literature on salvage treatments after focal therapy (FT) for prostate cancer (PCa).

Materials and methods

A non-systematic literature review was conducted on PubMed, Scopus, and Web of Science up to March 15, 2024, for studies that assessed salvage treatment outcomes in patients with recurrent PCa after primary FT. Original prospective and retrospective studies with more than 10 patients were included. Reviews, editorial comments, conference abstracts, and studies focusing solely on whole-gland treatments were excluded.

Results

Twenty-one studies with a total of 1012 patients were included. The most reported salvage treatments were salvage radical prostatectomy followed by re-do ablation therapy. Only one study evaluated salvage radiation therapy. Except for one prospective study, all studies were retrospective. Oncological outcomes showed acceptable biochemical recurrence rates. Functional outcomes varied, with significant impacts observed on erectile function across modalities, though continence rates were less impacted. Complications were generally low across all treatment options.

Conclusion

Salvage treatment post-primary FT is feasible, safe, and has reasonable oncologic outcomes. However, significant declines in sexual function are common, while continence is comparatively less affected. The literature primarily consists of retrospective studies; hence, future research should focus on large-scale prospective evaluations to better define treatment protocols and improve patient outcomes.

NETWORKING

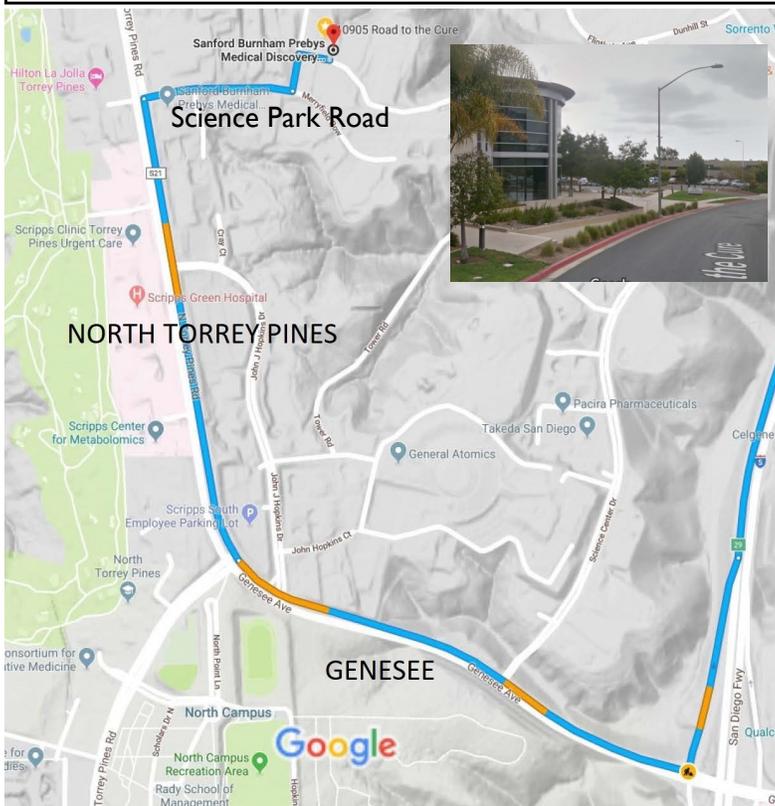
Please help us in our outreach efforts. Our speakers bureau consisting of Gene Van Vleet and Bill Lewis is available to speak to organizations of which you might be a member. Contact Bill 619-591-8670 (bill@ipcsg.org) to coordinate.

Member John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: <https://ipcsg.org/personal-experience>

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!



Directions to Sanford-Burnham-Prebys Auditorium 10905 Road to the Cure, San Diego, CA 92121

- Take I-5 (north or south) to the Genesee exit (west).
- Follow Genesee up the hill, staying right.
- Genesee rounds right onto North Torrey Pines Road.
- **Do not turn into the Sanford-Burnham-Prebys Medical Discovery Institute or Fishman Auditorium**
- Turn right on Science Park Road. Watch for our sign here.
- Turn Left on Torreyana Road. Watch for our sign here.
- Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.

DIRECTIONS TO MEETINGS