

GLOBAL SOCIETY OF RARE GU TUMORS

PHILIPPE E SPIESS, MD, MS, FRCs(C), FACS



President, Global Society of Rare Genitourinary Tumors

E-mail: Philippe.spiess@moffitt.org

National Comprehensive Cancer Network:

Vice-Chair, Bladder and Penile Cancer Panel

Moffitt Cancer Center:

Assistant Chief of Surgical Services

Senior member, Department of GU Oncology

Medical Director, Virtual Health



**SAN RAFFAELE
UROLOGIC ONCOLOGY
RETREAT**

**25 NOVEMBRE 2022 MILANO
AULA SAN RAFFAELE**

1st EDITION 2022



DISCLOSURES

I HAVE NO RELEVANT DISCLOSURES RELATED TO THIS TALK OR SUBJECT MATTER OTHER THAN SERVING AS: THE VICE-CHAIR OF THE NCCN BLADDER AND PENILE CANCER PANEL (LEADERSHIP ROLE ONLY) AND PRESIDENT OF THE GLOBAL SOCIETY OF RARE GU TUMORS©



OUTLINE



Historical Perspective



Organizational infrastructure



Early Efforts and Achievements



Conclusions



HISTORICAL PERSPECTIVE



GSRGT Mission

*Advance the Management of
Rare Genitourinary Tumors
through a Global Collaboration
of the Scientific Community*



ORGANIZATIONAL INFRASTRUCTURE



Global Society of Rare Genitourinary Tumors - Leadership Council



Philippe E Spiess, MD



Gareth Griffiths, PhD



Sarah Psutka, MD



Petros Grivas, MD



Andrea Necchi, MD



Jeanny Aragon-Ching, MD



Toni Choueiri, MD



Sumanta Pal, MD



Curtis Pettaway, MD



Lucia Nappi, MD



Gagan Prakash, MD



Karima Oualla, MD



Asif Muneer, MD



Maria Cario, MD



Jasreman Dhillon, MD



Wayne Earle



Alejandro Rodriguez, MD

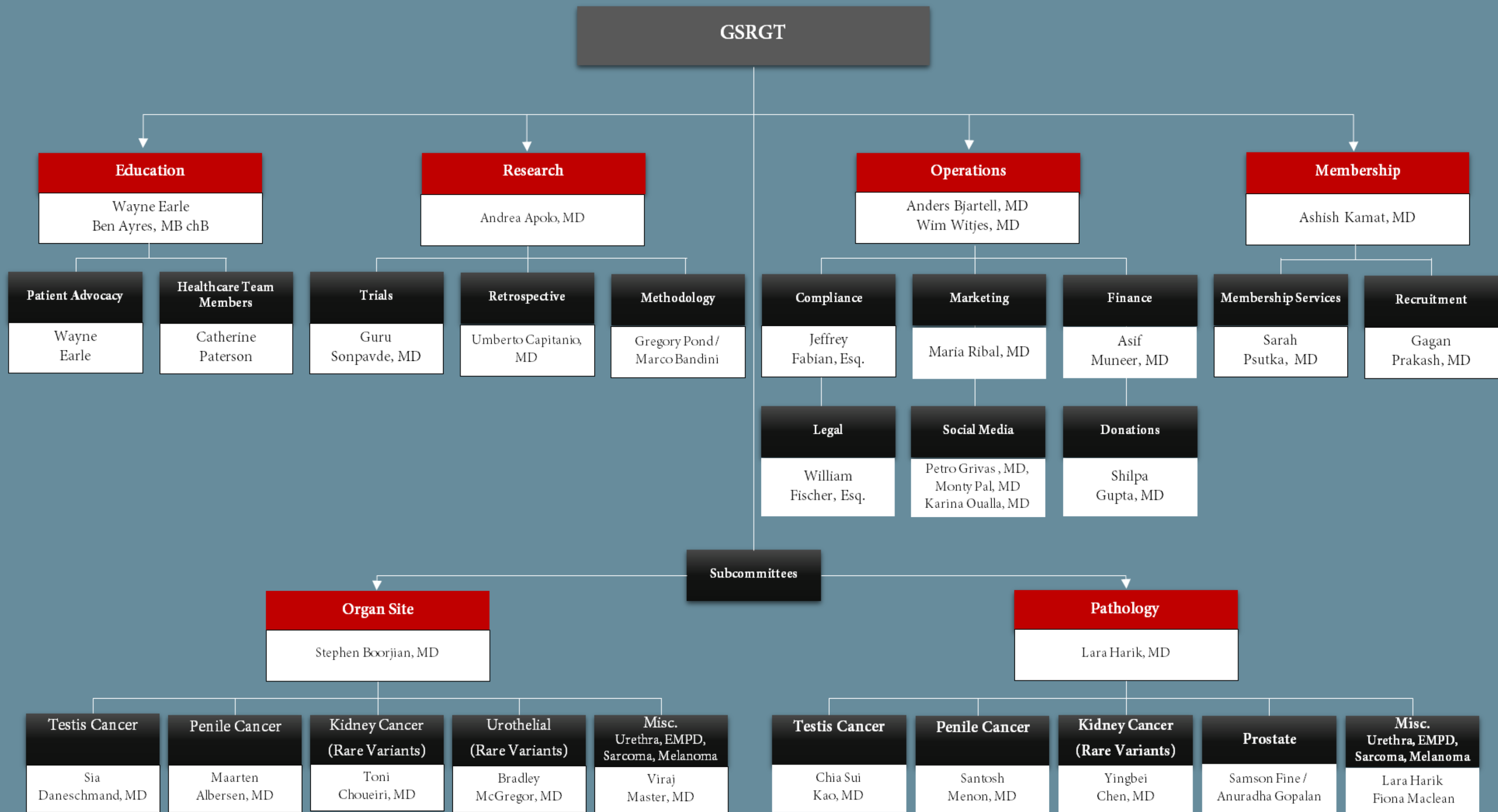


Shilpa Gupta, MD



Ding-Wei Ye, MD





EARLY EFFORTS & ACHIEVEMENTS



A global approach to improving penile cancer care

Marco Bandini, Mohamed Ahmed, Giuseppe Basile, Nicholas Watkin, Viraj Master, Yao Zhu, Gagan Prakash, Alejandro Rodriguez , Mbaaga K. Ssebakumba , Riccardo Leni, Giuseppe Ottone Cirulli, Ben Ayres, Rachel Compitello, Filippo Pederzoli , Pankaj M. Joshi, Sanjay B. Kulkarni, Francesco Montorsi, Guru Sonpavde , Andrea Necchi and Philippe E. Spiess

Continent or country, total n (%)	Registry	Number of publications by registry, n (%)
Asia 4 (5.8)	–	–
China 1 (1.4)	China Cancer Registry	1 (1.4)
Japan 1 (1.4)	Nationwide hospital cancer registry database	1 (1.4)
South Korea 2 (2.9)	KNCIDB (National Cancer Incidence Database)	1 (1.4)
	NHI (National Health Insurance Claim Database)	1 (1.4)
Europe 17 (24.7)	–	–
Denmark 6 (8.8)	DaPeCa (Danish Penile Cancer Database)	6 (8.9)
France 1 (1.4)	FRANCIM (French Network Cancer Registries)	1 (1.4)
Germany 1 (1.4)	Common Cancer Registry	1 (1.4)
Netherlands 1 (1.4)	PALGA (Pathologisch-Anatomisch Landelijk Geautomatiseerd Archief)	1 (1.4)
Norway 1 (1.4)	CRN (Cancer Registry of Norway)	1 (1.4)
Spain 1 (1.4)	CMBD (Conjuncto Minimo Basico de Datos)	1 (1.4)
Sweden 5 (7.4)	PenCBaSe (Penile Cancer Database Sweden)	2 (2.9)
	NPECR (National Penile Cancer Register)	2 (2.9)
	Swedish Family Cancer Database	1 (1.4)
UK 1 (1.4)	UK National Cancer Registry	1 (1.4)
North America 45 (65.2)	–	–
Canada 2 (2.9)	Canadian Cancer Registry	2 (2.9)
USA 43 (62.5)	NCDB (National Cancer Database)	23 (33.4)
	SEER (Surveillance, Epidemiology, and End Results)	13 (18.9)
	SHRI (State Health Registry of Iowa)	1 (1.4)
	DLD (Iowa Driver License Database)	1 (1.4)
	Iowa Oncology Registry	1 (1.4)
	Florida Cancer Data System	1 (1.4)
	National Inpatient Sample Database	1 (1.4)
	American Board of Urology Case Logs	1 (1.4)
	ACS National Surgical Quality Improvement Program	1 (1.4)
Oceania 2 (2.9)	–	–
Australia 2 (2.9)	Central Cancer Registry	1 (1.4)
	South Australian Cancer Registry	1 (1.4)
South America 1 (1.4)	–	–
Brazil 1 (1.4)	Brazilian Public Health System Database	1 (1.4)



TABLE 4

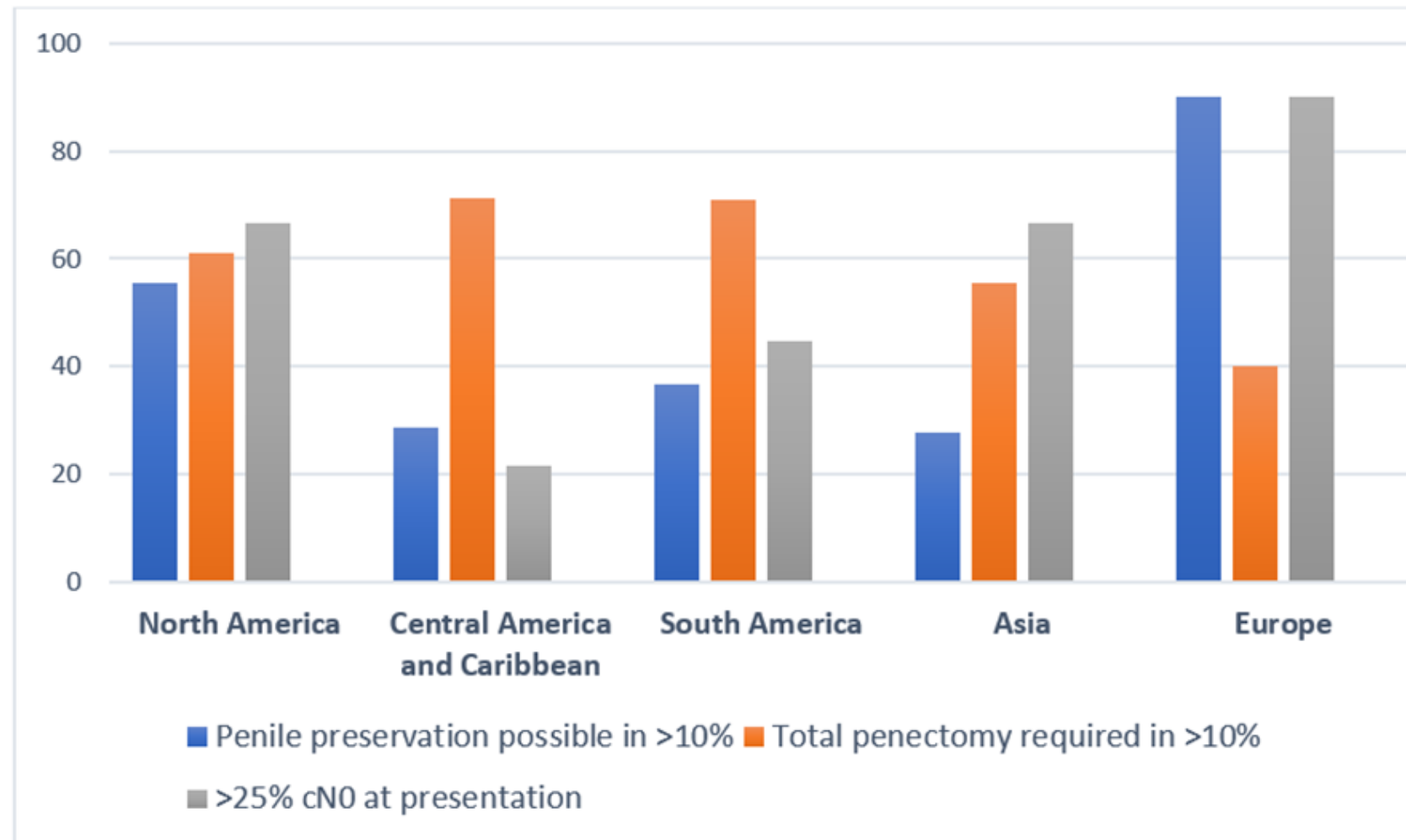
Points with and Without Consensus from the SUO and eUROGEN Surveys.

Points with consensus	Points without consensus
Decision-making considerations	
Performing inguinal LND for a clinically node negative patient with a high-risk primary Preoperative chemotherapy for patients with bulky inguinal nodes	The approach to performing inguinal LND (MILD, SILD, DSNB, and VEIL) The choice of chemotherapeutic agents and regimen
Intraoperative considerations	
<i>For inguinal LND</i> <ul style="list-style-type: none"> • Transverse incision (and not the “lazy S” or vertical) • Inferior, lateral and medial borders of the template 	<i>For inguinal LND</i> <ul style="list-style-type: none"> • Site of transverse incision • Lateral border of the template • Choice of template MILD or SILD and their comparative outcome
<i>For DSNB</i> <ul style="list-style-type: none"> • False-negative rate documented • Hybrid technique standardized • Least complication rate among all procedures for cN0 	<i>For DSNB</i> <ul style="list-style-type: none"> • Quantity and injection sites for radiotracer/blue dye/ICG • Preferred incision site • Preferred combination in case of dual tracer • Choice of ICG equipment
Specific ligation of lymphatics during inguinal LND	The method of specific ligation of lymphatics (vessel sealing devices/clips)
Use of inguinal drains after LND	Using intra-operative frozen section analysis during inguinal LND
Postoperative considerations	
Use of postoperative antibiotics	Duration and choice of postoperative antibiotics
Use of prophylactic anticoagulation	Duration of prophylactic anticoagulation Use of prophylactic stockings to prevent lymphedema Drainage volume before removal of drain



Global variations in practice patterns in penile cancer management- Insights for collaborative research from a GSRGT-led survey

Prakash G et al. (Submission to JCO Global Oncology)



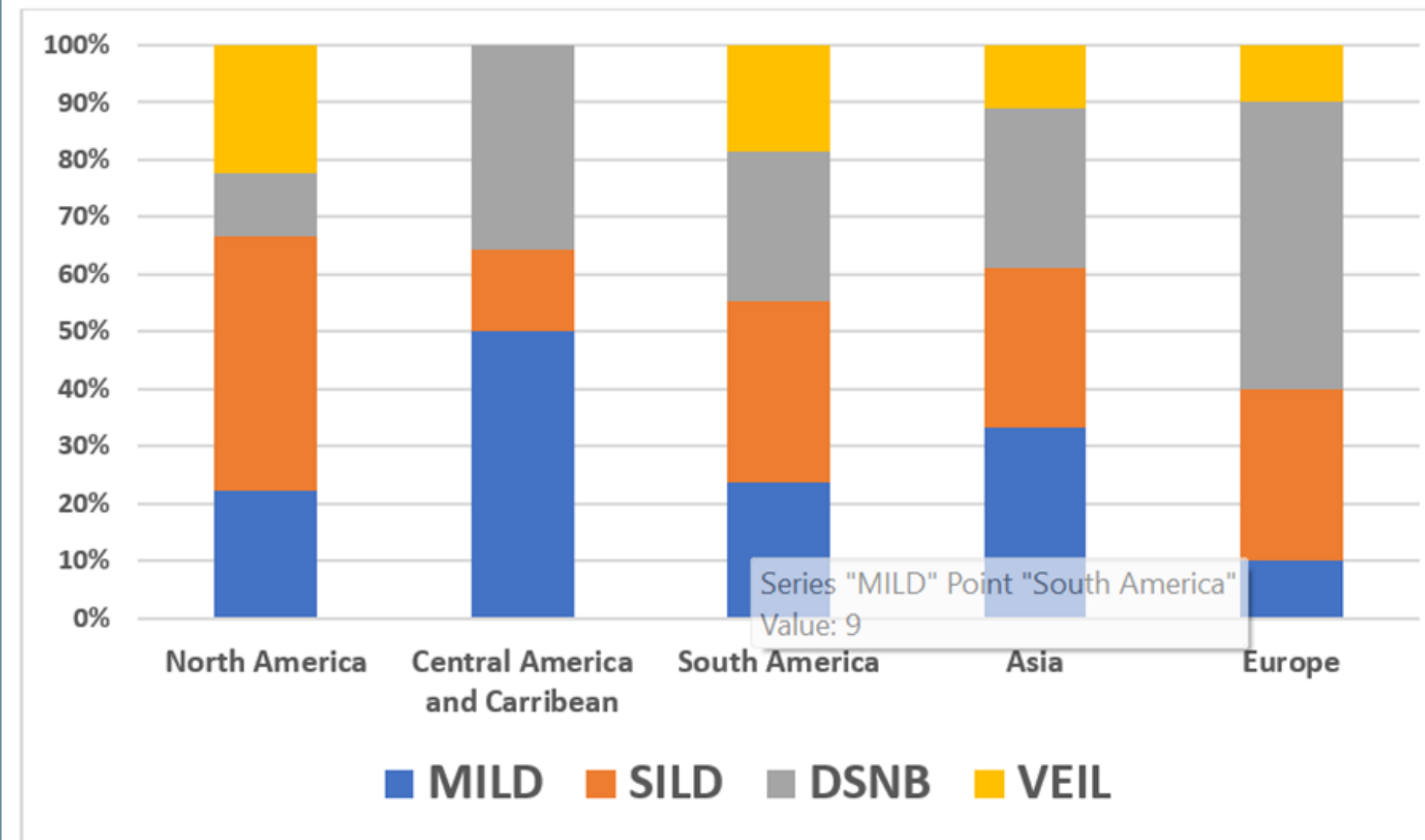
Percentage of respondents who answered that 'penile preservation is possible in >10%', 'total penectomy is required in >10%' and that '>25% of their patients are cN0 at presentation'.



Global variations in practice patterns in penile cancer management- Insights for collaborative research from a GSRGT-led survey

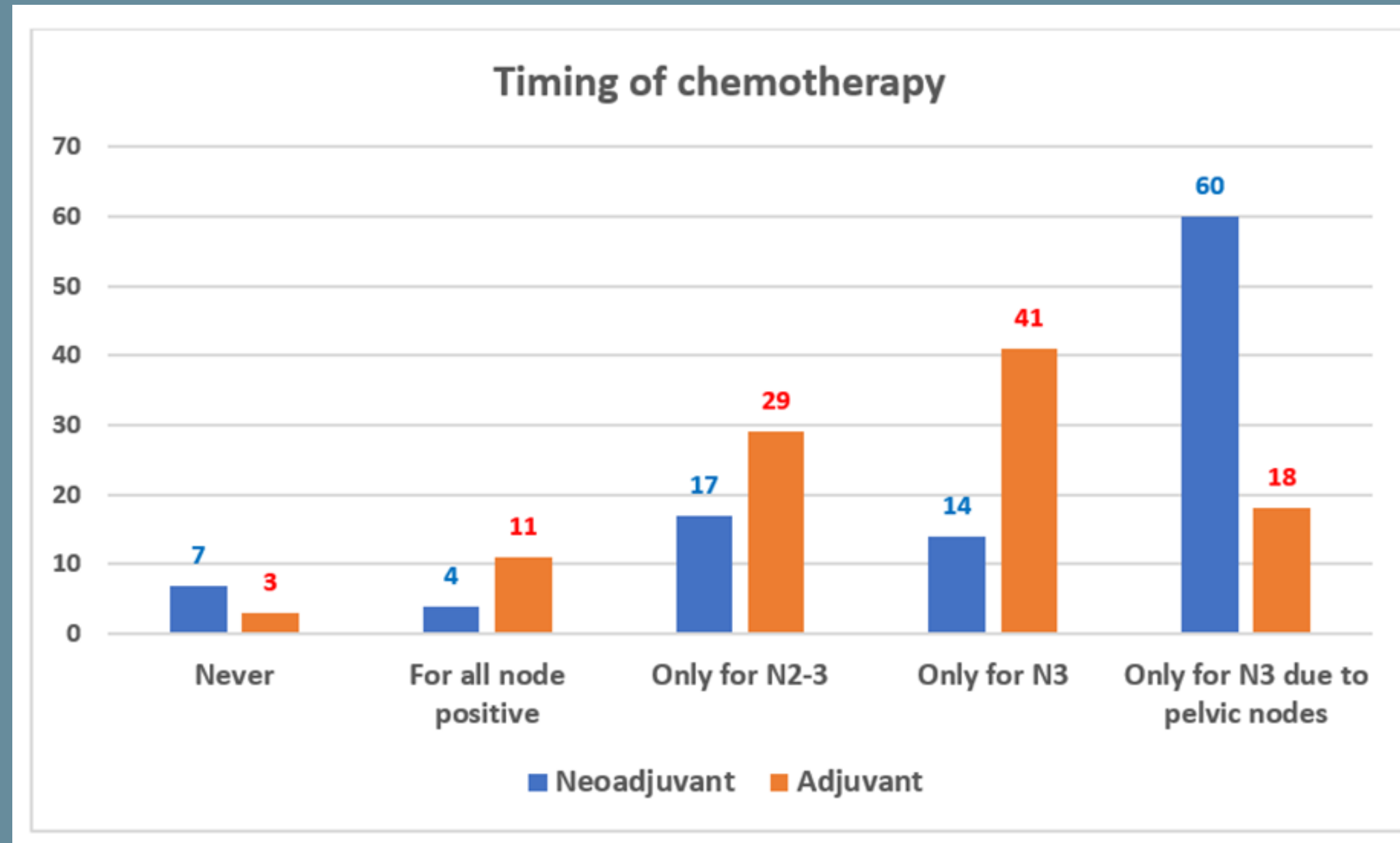
Prakash G et al. (Submission to JCO Global Oncology)

Preferred modality for invasive nodal staging



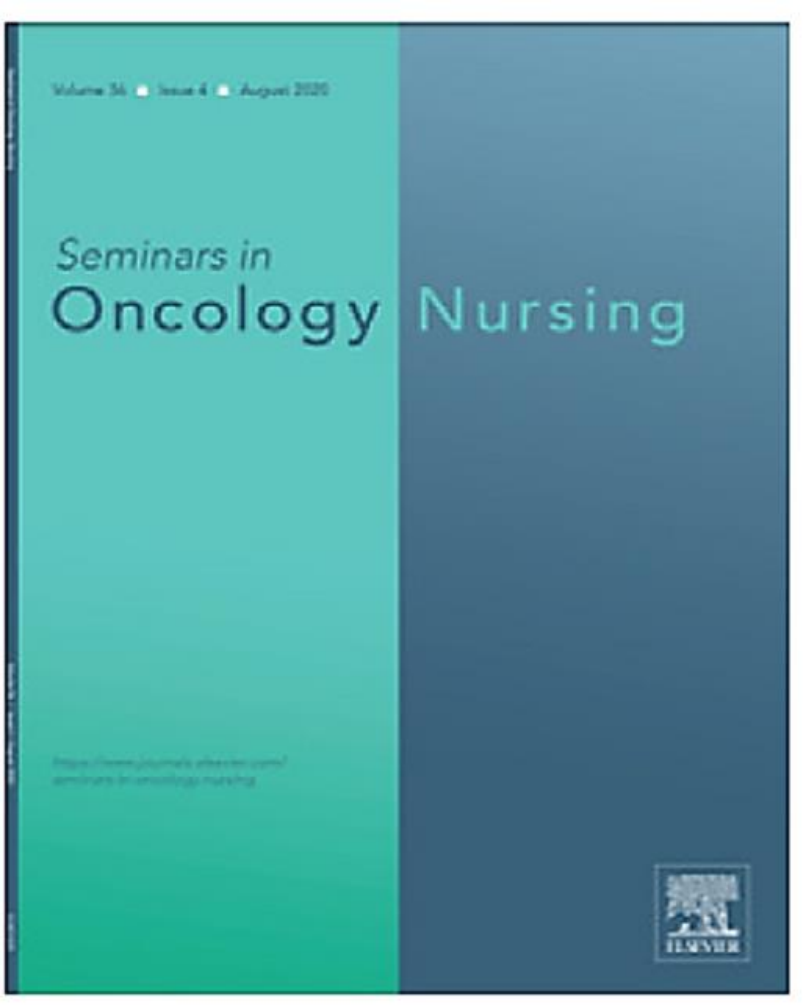
Global variations in practice patterns in penile cancer management- Insights for collaborative research from a GSRGT-led survey

Prakash G et al. (Submission to JCO Global Oncology)



Current unmet Needs in penile cancer: the way forward?

Rob Cornes, Wayne Earle



TABLE

Penile Cancer Information and Support.

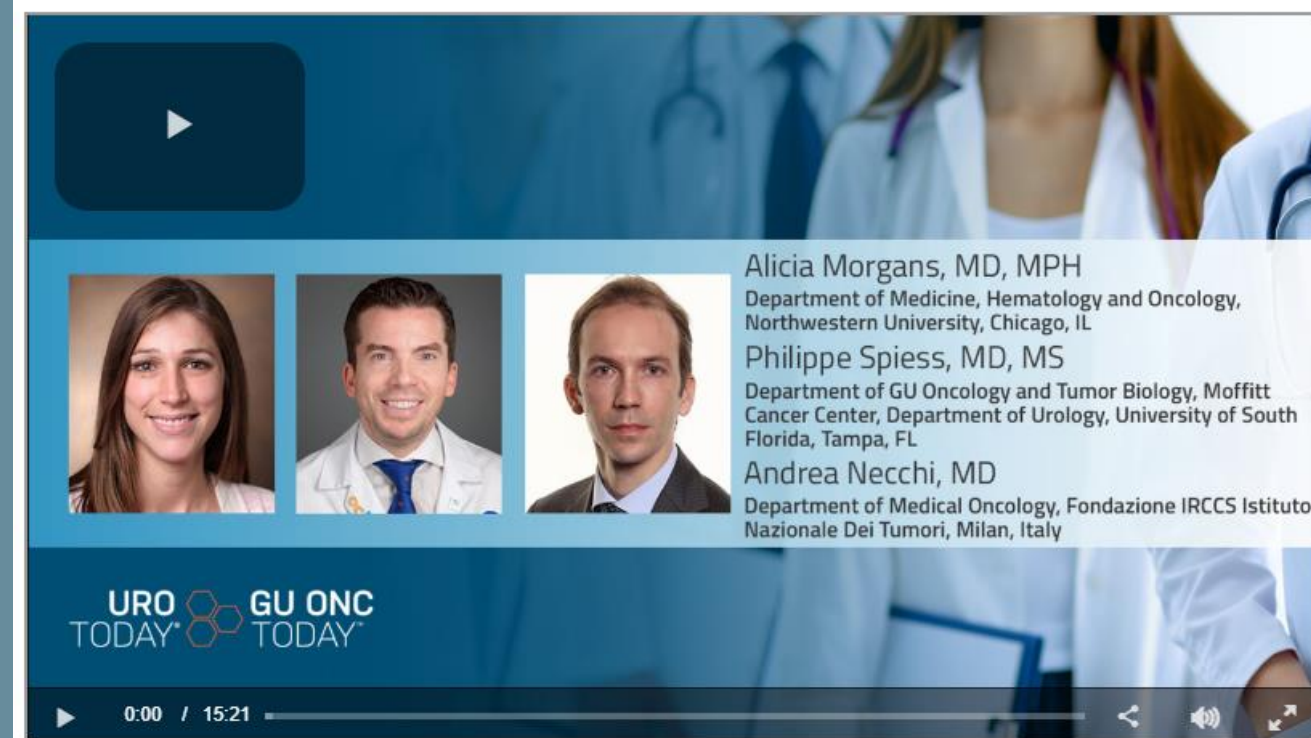
Global Sources of Information and Support for Penile Cancer	
Penile Cancer Awareness and Support (online Facebook Support Group)	https://www.facebook.com/groups/penilemelanoma/
Orchid Male Cancer UK	https://orchid-cancer.org.uk
Telephone Counseling Service (penile and testicular)	https://orchid-cancer.org.uk/penile-cancer/coping/telephone-counselling-service/
Scottish Penile Cancer Support Group	https://orchid-cancer.org.uk/penile-cancer/penile-cancer-support-service-scotland/
Penile Cancer Booklet	https://orchid-cancer.org.uk/wp-content/uploads/2020/04/Penile-Cancer-Booklet-1.pdf
Pocket Rocket Awareness Z-Card	https://orchid-cancer.org.uk/wp-content/uploads/2021/01/1091-Pocket-Rocket-web.pdf
Other resources	https://orchid-cancer.org.uk/awareness-education/information/
Willy Walk 2022	Contact: dani.freedland@orchid-cancer.org.uk https://www.youtube.com/watch?v=OPLJX_GU4Ao https://www.youtube.com/watch?v=wPC6E44Twz4 Contact: robert.cornes@orchid-cancer.org.uk
Check Your Tackle Male Cancer	https://www.checkyourtackle.com/ Contact: wayne@checkyourtackle.com
University College Hospitals (London, UK) Penile Cancer Support Group	https://www.uclh.nhs.uk/our-services/find-service/cancer-services/cancer-academy/cancer-academy-schools/education-programme-people-affected-cancer/course-template-12 Contact: Sadie Molloy, Clinical Nurse Specialist uclh.supportandinformation@nhs.net
UCAN	https://www.ucanaberdeen.com/
GSRGT	https://www.gsrgt.com/
eUrogen	https://eurogen-ern.eu/

eUrogen, European Reference Network on urogenital diseases and conditions; GSRGT, Global Society of Rare Genitourinary Tumors; UCAN, urological CANcer charity.



LAST 18 MONTHS

Global Society of Rare Genitourinary Tumors (GSRGT) - Andrea Necchi & Philippe Spiess



OUTREACH

Organized major international conferences (Global Symposiums, Online Journal Clubs and Tumor Boards, Patient Advocacy Educational Sessions and Pathology Subcommittee Webinars)

PUBLICATIONS

Led 4 special issues of journals dedicated to rare GU tumors (European Urology Focus, Current Opinion in Urology, Seminars in Nursing Oncology, and Asian Journal of Urology)

INTERNATIONAL PRESENCE

GSRGT has been featured at major international scientific conferences (EAU, CAU, and SIU)

MARKETING

Launched a website dedicated to rare GU tumors for clinicians and patients



GLOBAL RECOGNITION



**Confederación
Americana de
Urología**



European
Association
of Urology

OncoLive®



**URO
TODAY**®

The ASCO Post



SUBCOMMITTEES



Adrenal Tumor Subcommittee



JULIE HALLANGER JOHNSON, MD

Program Leader, Endocrinology Program

Moffitt Cancer Center



ALEXANDER KUTIKOV, MD

Chief, Division of Urology and
Urologic Oncology

Fox Chase



MARSHALL STROTHER, MD

Assistant Professor of Urology

Oregon Health & Science University



Global Society of Rare Genitourinary Tumors - Adrenal Subcommittee



ALEXANDER KUTIKIV, MD
Director



JULIE HALLANGER JOHNSON, MD
Moffitt Cancer Center &
Research Institute



MARSHALL STROTHER, MD
Oregon Health and Science
University



RENU EAPEN, MD
MacCallum Cancer Centre



CARLO ANDREA BRAVI, MD
Onze Lieve Vrouw Hospital



BENJAMIN RISTAU, MD
University of
Connecticut



Adrenal Tumor Subcommittee



Inaugural Initiative: www.adrenalmass.org

AdrenalMass.org

Management Guidance | Resources | About Us | References

Management Guidance

- Overview
- Hormonal Workup
- Imaging Assessment
- Biopsy
- Treatment
- Follow Up

Management Algorithm

Guidance on the work up and treatment of adrenal masses

Resources

- Resources Overview
- Instructions: Hormonal Testing
- Sample prescription: Hormonal Testing
- Laparoscopic Adrenalectomy Handout
- External Links

A flowchart with a central box labeled 'BOTH criteria met'. To its left are two boxes: '>20%' and '>5mm'. A red arrow points from the 'Management Guidance' menu to the flowchart. A green arrow points from the 'Resources' menu to the flowchart.



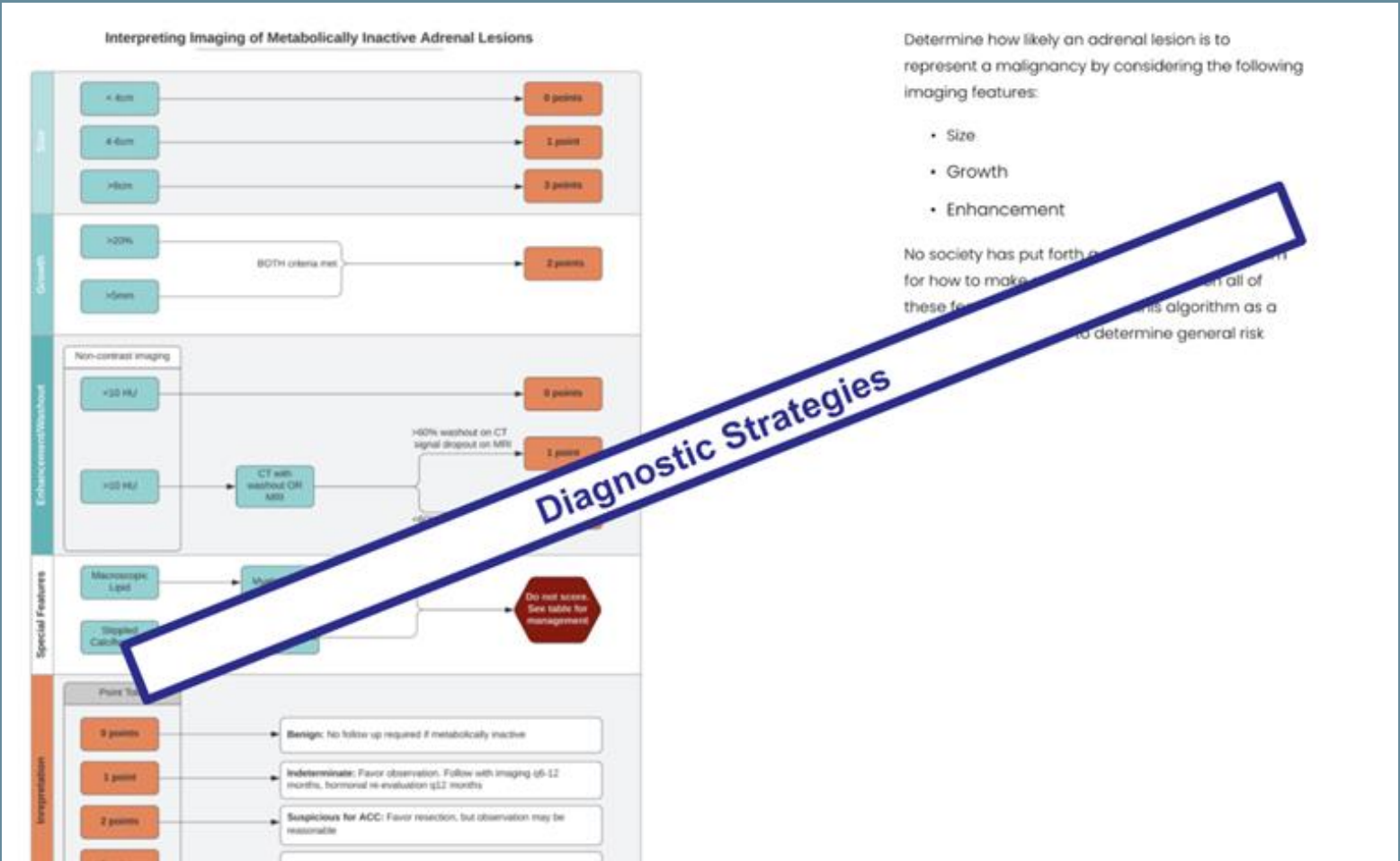


AdrenalMass.org

Management GuidanceResourcesAbout UsReferences

Treatment by Mass Type

	Addition	Management	Perioperative Care	Surgical Approach
Aldosterone-secreting	Adrenal vein sampling, but almost definitely not beneficial in patients <40 yo with clear unilateral adenoma on imaging -consider genetic testing	Total adrenalectomy (partial adrenalectomy discouraged due to high prevalence of multifocal disease in affected gland)	Postop: high sodium diet, monitor for hyperkalemia, measure aldosterone-to-renin ratio	Minimally invasive surgery preferred if feasible
Cortisol-secreting	Consider w/u for: -osteoporosis -urolithiasis	-Overt Cushing -> resection -Autonomous cortisol secretion w/o Cushing -> resection vs observation	Postop: monitor vitals for signs of Addisonian crisis, consider glucocorticoid supplementation	Minimally invasive surgery preferred if feasible





ROGER LI, MD

Dept. of GU Oncology

Moffitt Cancer Center

Our Mission

*To develop deeper understanding of rare GU tumors
through multi-omics approach*



Global Society of Rare Genitourinary Tumors - Genomics Subcommittee



BISHOY FALTAS, MD
Cornell University



Jeffrey Ross, MD
Foundation Medicine



Aditya Bagrodia, MD
University of California
San Diego



Daniel Grass, MD
Moffitt Cancer Center &
Research Institute



VASMI PARIMI, MD
Foundation Medicine



ANDREA APOLO, MD
National Cancer Institute

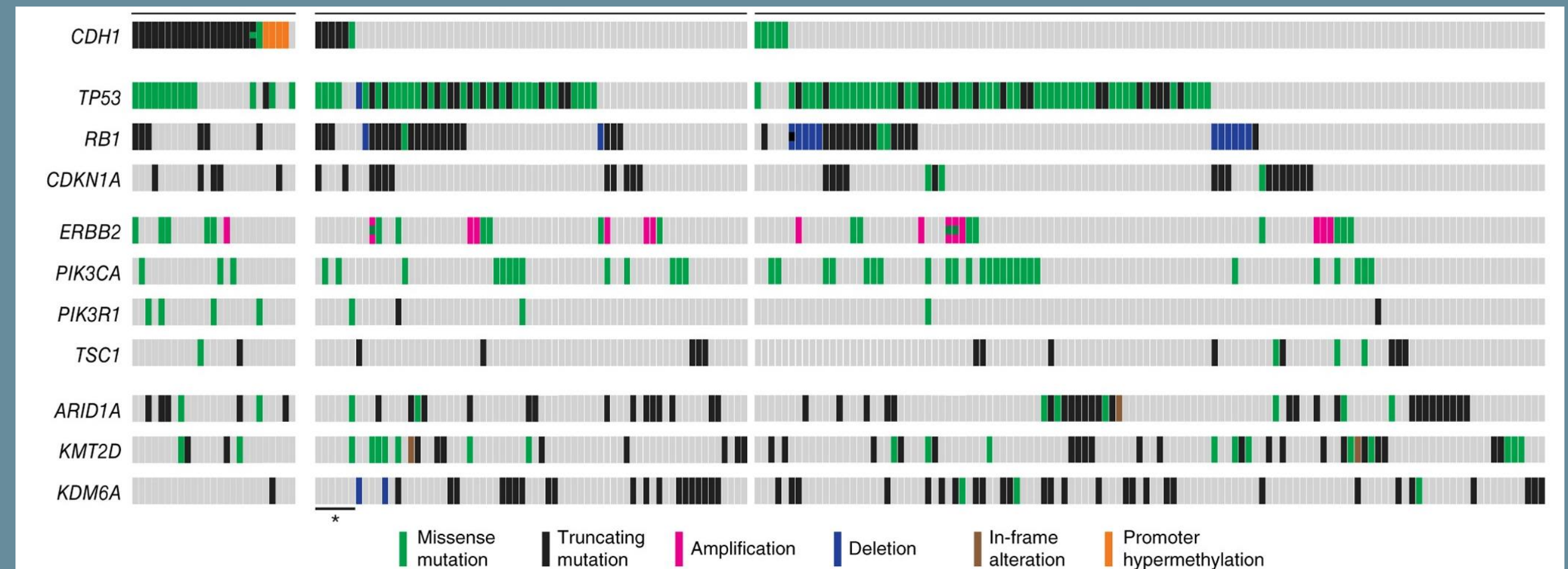
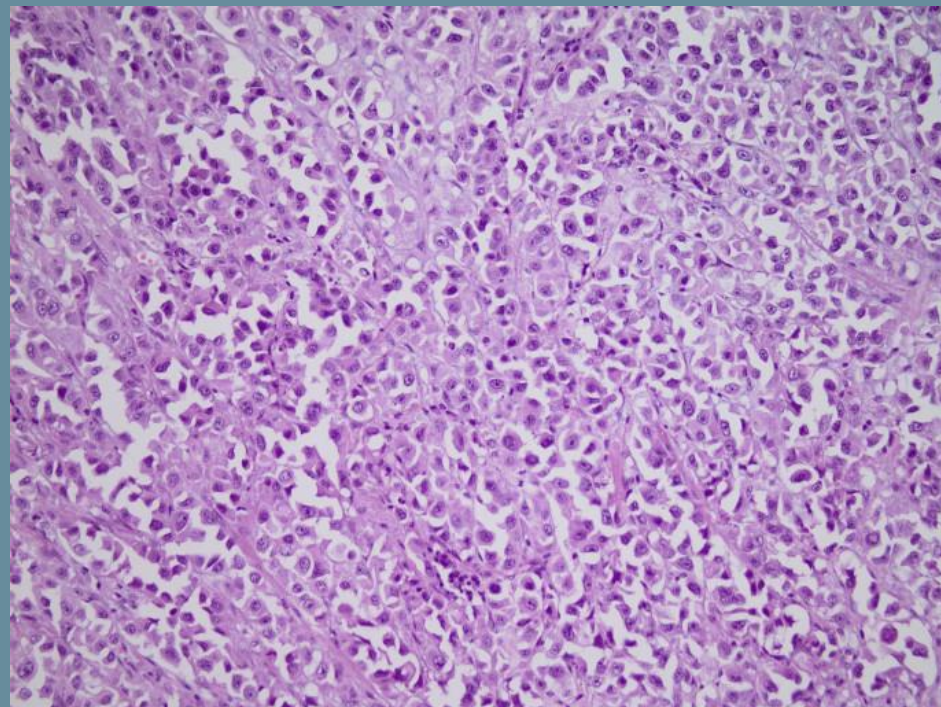


Kyle Rose, MD
Ochsner Health

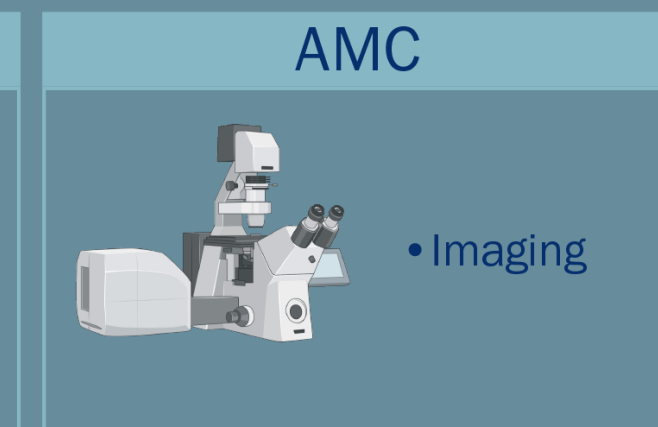
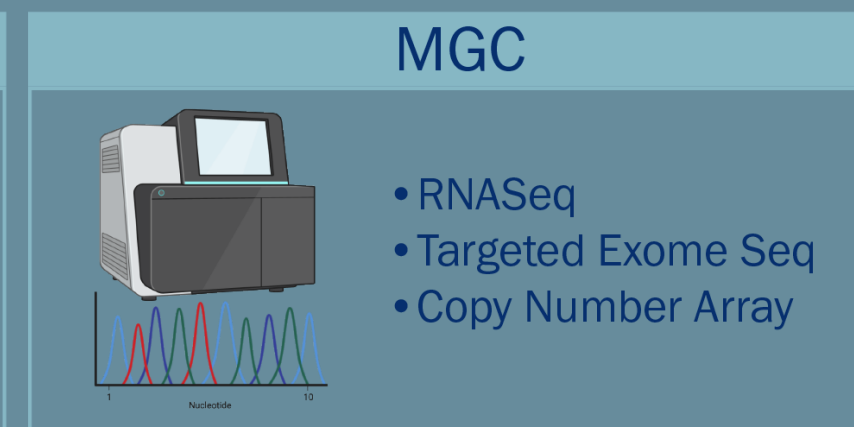
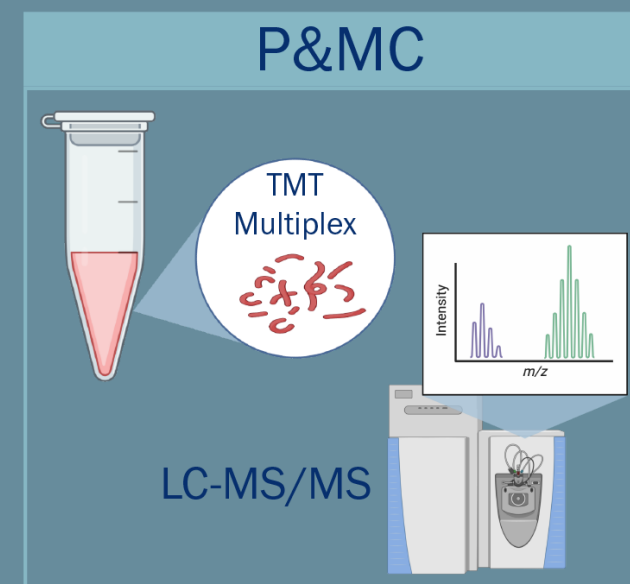
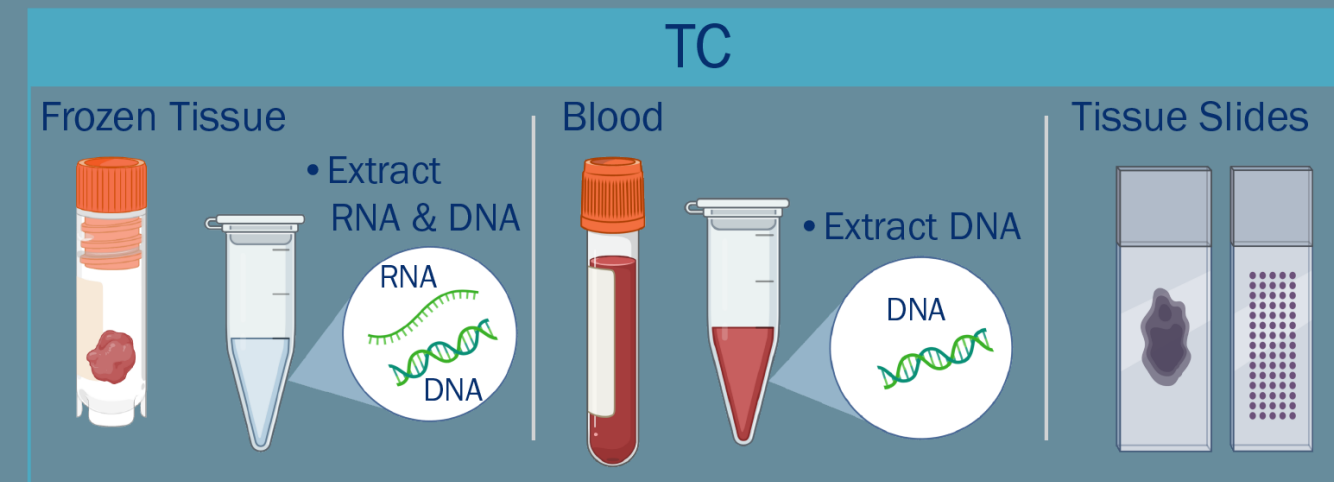
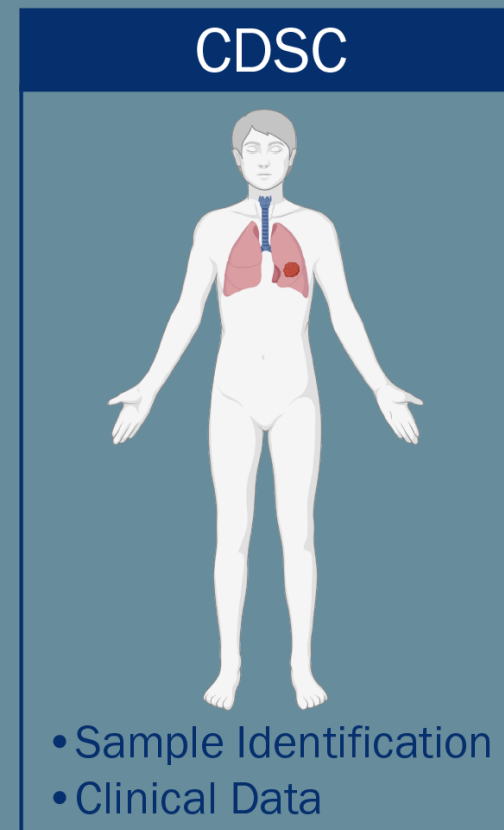




Inaugural initiative: Genomic Characterization of Plasmacytoid Bladder Cancer



Genomics Subcommittee



Workflow





LARA HARIK, MD

Director, Pathology Subcommittee

Emory

Our Mission

We are dedicated to fighting diagnostic & therapeutic disparities of rare GU tumors by promoting global education & research collaborations



Global Society of Rare Genitourinary Tumors - Pathology Subcommittee



LARA HARIK, MD
Director
Specialty: Urethra/EMPD/
Sarcoma/Melanoma



HIKMAT A. AL-AHMADIE, MD
Specialty: Bladder Cancer



SANTOSH MENON, MD
Specialty: Penile
Cancer



CHIA SUI KAO, MD
Specialty: Testis
Cancer



YINGBEI CHEN, MD, PhD
Specialty: Kidney
Cancer



HENNING REIS, MD
Specialty: Bladder
Cancer



SAMSON W. FINE, MD
Specialty: Prostate
Cancer



DANIEL BERNEY, MD
Specialty: Testis
Cancer



CHRIS PRZYBYCIN, MD
Specialty: Kidney
Cancer



PHEROZE TAMBOLI, MD
Specialty: Penile Cancer



ANURADHA GOPALAN, MD
Specialty: Prostate Cancer



FIONA MACLEAN, MD
Specialty: Urethra/EMPD/
Sarcoma/Melanoma



ANTONIO CUBILLA, MD
Member at Large



JEFFREY S. ROSS, MD
Member



JASREMAN DHILLON, MD
Member



ACHIEVEMENTS



CONFERENCES

The pathology subcommittee has had two successful webinars raising awareness on penile and urinary tract tumors. Both webinars were well attended with up to 600 registrants spanning across all continents

MEMBERSHIP

As a result of our successful outreach, the pathology subcommittee has over 450 members

FUTURE DIRECTIONS

Our plan is to open several multi-institutional studies on Rare GU tumors over the coming months

THE PATHOLOGY COMMITTEE OF THE GLOBAL SOCIETY OF RARE GENITOURINARY TUMORS

EVOLUTION IN PENILE CANCER 2021 UPDATE

AGENDA
Program Committee: Lara Harik, MD, Emory University
Samson Fine, MD, Memorial Sloan Kettering
Santosh Menon, MD, Tata Memorial Hospital

Welcome remarks

Comprehensive Review of Penile Anatomy and Prosection of Penile Tumors
Isabel Alvarado-Cabrero, MD

Penile Intraepithelial Neoplasia, HPV Associated and HPV Independent
Elsa Velazquez, MD

Updates on Management of Penile Tumors: Challenges in Imaging
Curtis Pettaway, MD

Updates and Challenges in Staging of Penile Tumors
Pheroze Tamboli, MD

Clinical and Pathological Features of HPV Associated and HPV Independent Penile Tumors
Antonio Cubilla, MD

Comparative genomics of HPV Positive versus HPV Negative Penile Tumors
Jeff Ross, MD

Case based presentation: Leiomyosarcoma of penis and differential diagnosis
Santosh Menon, MD

Case based presentation: Extra-Mammary Paget Disease
Lara Harik, MD

Concluding Remarks
Townhall open discussion forum
Adjourn!

URINARY TRACT: DIAGNOSTIC CHALLENGES AND THERAPEUTIC UPDATES

The Pathology Committee of the Global Society of Rare Genitourinary Tumors PRESENTS

SATURDAY, OCTOBER 30, 2021 ZOOM WEBINAR 8:00 AM - 12:30 PM EST

FACULTY

Victor Reuter, MD MEMORIAL SLOAN KETTERING CANCER CENTER	Hikmat Al-Ahmadie, MD MEMORIAL SLOAN KETTERING CANCER CENTER	Henning Reis, MD GOETHE UNIVERSITY HOSPITAL, FRANKFURT	Fiona Maclean, MBBS DOUGLASS HANLY MOIR, MACQUARIE UNIVERSITY
Gopa Iyer, MD MEMORIAL SLOAN KETTERING CANCER CENTER	Priti Lal, MD PERLEMAN SCHOOL OF MEDICINE	Charles Anunobi, MBBS LAGOS UNIVERSITY TEACHING HOSPITAL	Nadine Galsa, MD RWTH AACHEN UNIVERSITY HOSPITAL

Visit www.gsrct.com for more information about the event.

REGISTER



CONCLUSIONS



GSRGT GLOBAL SUMMIT



GLOBAL SUMMIT

Overall the 1st GSRGT Virtual Summit had over 400 attendees and continued views on the gsrgt website

Surveys have shown positive feedback for both Day 1: Penile Cancer & Day 2: Testis Cancer

All sessions received great reviews including the keynote, testimonials, case discussions and research updates alike

REVIEWS

"I truly believe the virtual setting has as much or more value than the live meetings and hopefully will continue to be an option as travel begins to open once again"

"Great lectures! I think you can continue to expand the presence of GSRGT, by making more collaborations with researchers outside US/EU"



OUTREACH


OPPORTUNITIES

GLOBAL SUMMIT

An international symposium featuring thought leaders on featured rare tumor topics highlighting advances in the management and innovative clinical trials. There will be sessions dedicated to outreach, research and advocacy.

GSRG T PATHOLOGY

A very illustrious group of top international genitourinary pathologists developing educational materials including webinars and other resources. To advance our research and our understanding, diagnostic accuracy, and prognostic characterization of these rare tumors.



GLOBAL TUMOR BOARDS



Multi-disciplinary tumors boards highlighting important clinical and surgical considerations in the management of specific rare GU tumors in addition to promoting pivotal clinical trials being conducted in these areas globally.

COLLABORATIONS

The global society is dedicated to fostering a community of collaboration between colleagues dedicated to the care of these tumors across the world importantly in parts of the world such efforts can be expanded and promoted.


PATIENT ADVOCACY

Our society is very much dedicated to promoting and expanding patient education and patient advocacy efforts for rare GU tumors globally.



MAIN OFFICE

16313 Millan de Avila, Tampa, FL 33613, USA
Email: gsgt.inc@gmail.com
Members: gsgtmembers@gmail.com
@GTumors



Global Society of Rare Genitourinary Tumors

"solely dedicated to advancing the care for
rare genitourinary tumors"

Website: www.gsgt.com

SOCIETY MISSION

EDUCATION

To improve the knowledge on rare GU tumors globally within the healthcare community and among patients as well as their families.

RESEARCH

To advance the care of rare GU tumors throughout the international community through novel scientific research and promotion of innovative clinical trials.

PATIENT ADVOCACY

To address and bring attention to the clinical and emotional needs of patients impacted by these tumors.

PATHOLOGY

Improve the knowledge and expertise in diagnosing rare GU tumors across the global community through education initiatives.

ORGAN SITE

Disease site focused committees of international thought leaders developing and promoting education and research on these specific topics for our society.



ABOUT US

This society was created as an impetus that these rare genitourinary tumors are often poorly studied nor understood and that a dedicated society focused on them would be quite impactful in improving patient outcomes and quality of life in addition to fostering opportunities for research collaborations.

The society aims to focus its activity around penile, testicular, rare variants of various genitourinary tumors, upper tract, urethral, adrenal cancer, and other rare tumors.

PRESIDENT

Philippe E Spiess, M.D

VICE PRESIDENT

Andrea Necchi, M.D.

DIRECTOR OF OPERATIONS

Anders Bjartell, MD, PhD

DIRECTOR OF MARKETING

Maria J Ribal, M.D.

SECRETARY

Curtis A Pettaway, M.D.

COUNCILOR AT LARGE

Shilpa Gupta, M.D.
Gareth Griffiths, PhD
Sarah P. Psutka, M.D.

TREASURER

Asif Muneer, M.D.

PATIENT ADVOCACY

Mr. Wayne Earle
Benjamin Ayres, M.D.



OUTREACH



Email Newsletter


MMMM YYYY | Volume 1, Number 1

Global Society of Rare Genitourinary Tumors

Global Society of Rare GU Tumors (GSRGT) is an international society created to respond to special needs in the field of rare genitourinary cancers. It has an educational and research mission to promote evidence based diagnostic and treatment standards for rare GU malignancies globally. The GSRGT conducts its missions in parallel with other societies (e.g. IRCl) and remains in close contact with these societies.

"Solely dedicated to advancing the care for rare genitourinary tumors"

These tumors are highly heterogenous and often non-optimized across the world. Unfortunately, these cancers are often poorly studied based on the paucity of cases cared for outside of tertiary care referral and/or supra-regionalization center. Additionally the society incorporates patient advocacy aiming to provide support to patients living with rare urological cancer, to raise public awareness of these tumors, to advance cancer research, to improve the quality of cancer care, and also address the legislative and regulatory issues that may affect cancer care.



Dr. Philippe Spiess

Virtual Summit 2020

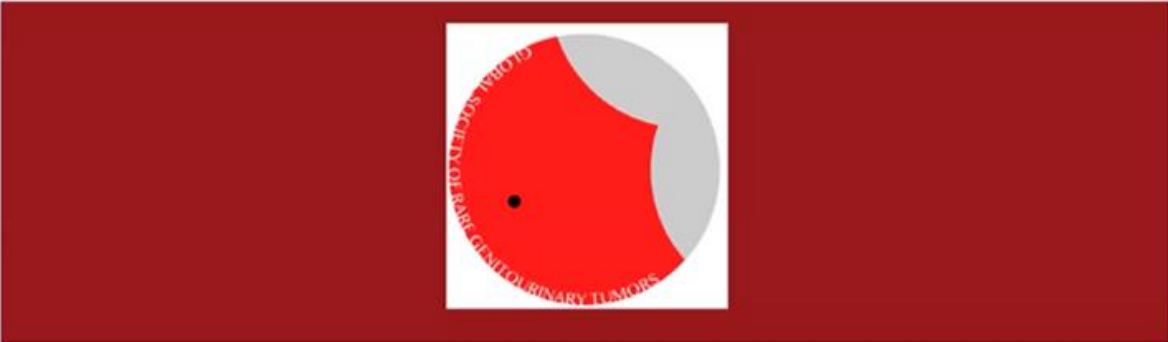
The society held its first annual meeting on December 11-12, 2020 as a virtual meeting due to current COVID 19 pandemic situation and was dedicated to penile and testis cancer. More than 480 participants from the 5 continents came together, and overall, the 1st summit was a great success.

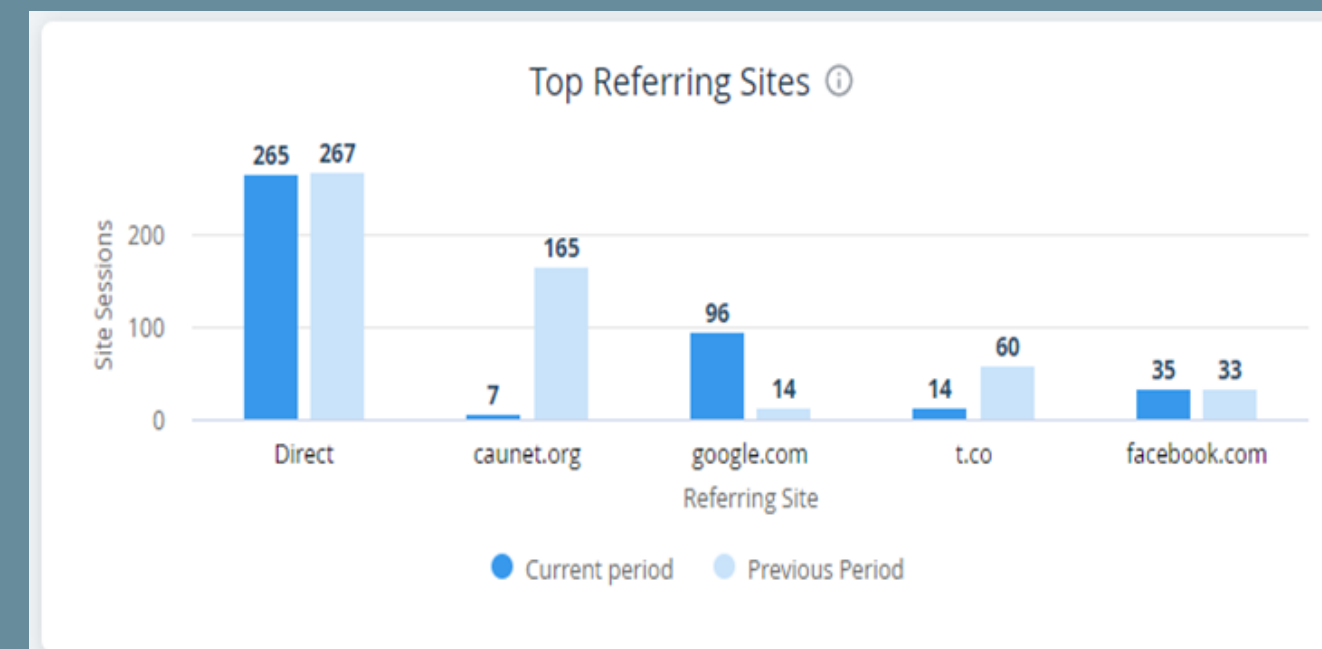
Day 1: Penile Cancer

Philippe Spiess, Genitourinary Surgical Oncologist and the Assistant Chief of Surgical Services at the Moffitt Cancer Center, and Andrea Necchi, Associate

GLOBAL SOCIETY OF RARE GENITOURINARY TUMORS –VIRTUAL TUMOR BOARD

FEBRUARY 5, 2021







Global Partnerships
Funding Opportunities



Global Society of Rare Genitourinary Tumors (GSRGT)

To advance the management of rare genitourinary tumors through a global collaboration of the scientific community



- Website: www.gsrgt.com
- Twitter: @Gtumor
- Philippe E Spiess, MD
Email: philippe.spiess@moffitt.org
- Andrea Necchi, MD
Email: andrea.necchi@istitutotumori.mi.it



What is on the horizon for the GSRGT



Clinical Trials

Our mission is to lead Innovative Global Trials



Patient Advocacy

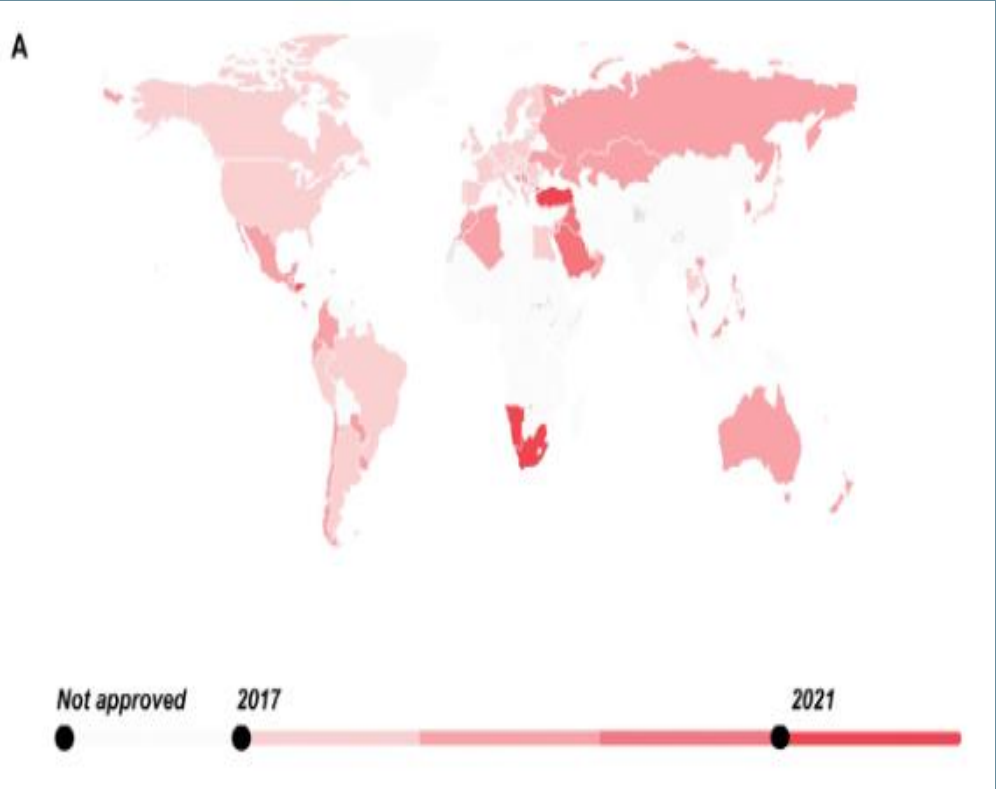
Promote efforts in patient advocacy



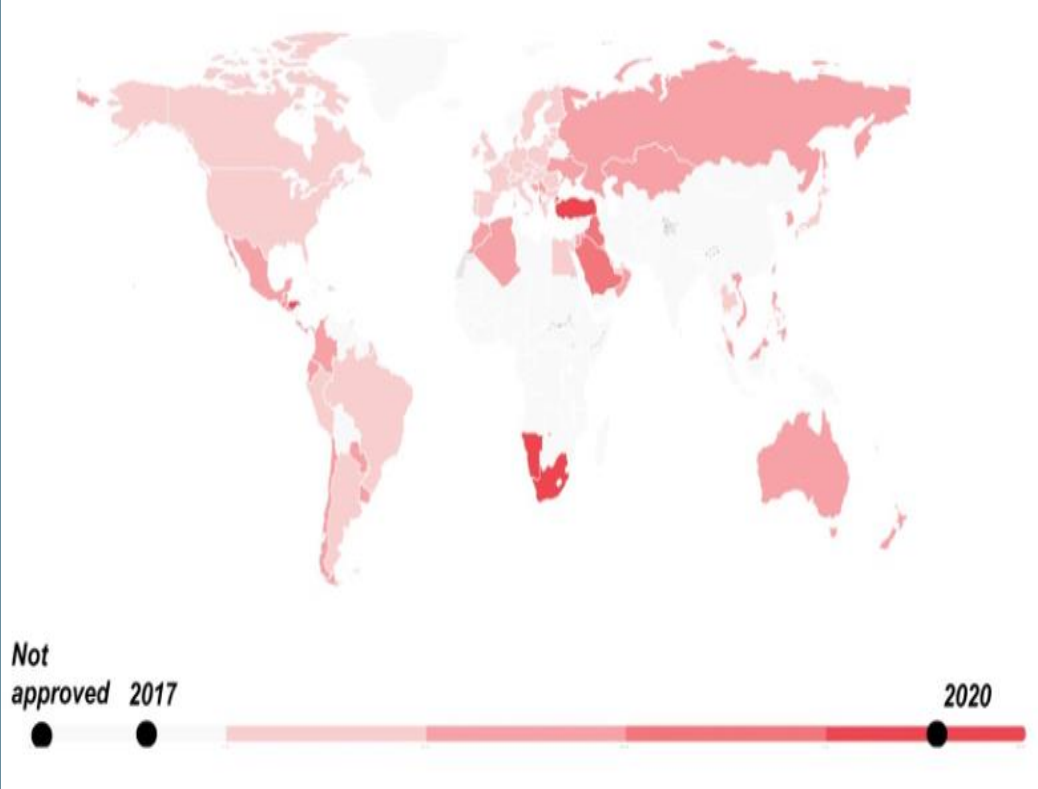
Addressing the critical need of access to potentially curative systemic therapies

Disparities in Access to Novel Systemic Therapies in Patients With Urinary Tract Cancer: Propagating Access, Policies and Resources Uniformly

Andrea Necchi,^{1,2} Monika Joshi,³ Rick Bangs,^{4,5} Lydia Makaroff,⁶ Petros Grivas,⁷ Ashish M. Kamat,⁸ Wassim Kassouf,⁹ Daniele Raggi,² Laura Marandino,² Tracey Krupski,¹⁰ Thomas W. Flaig,¹¹ Philippe E. Spiess¹², on behalf of the Global Society of Rare Genitourinary Tumors (GSRGT) and the International Bladder Cancer Group (IBCG)

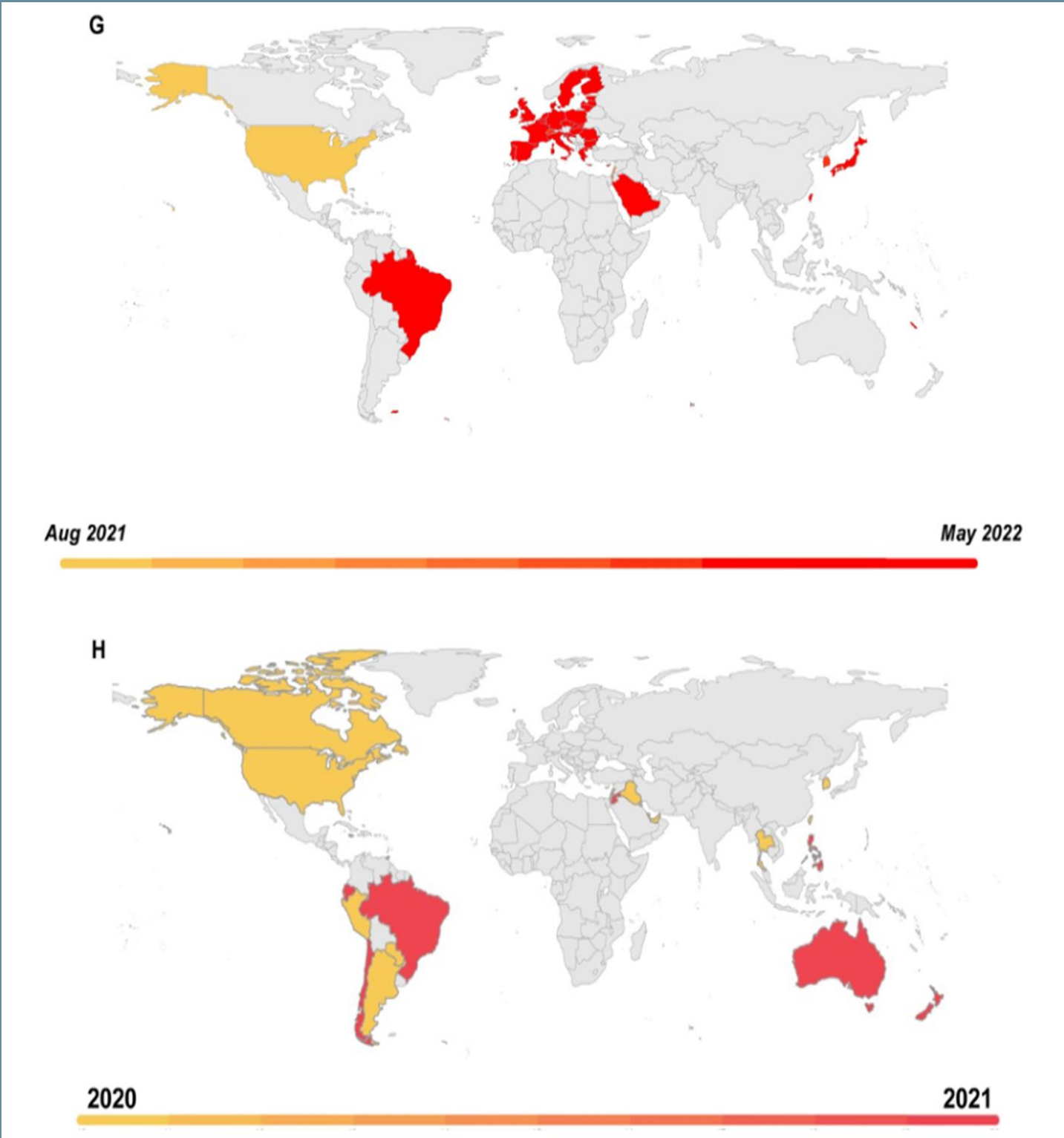


Pembro in mUC (1st line)



Pembro in mUC (salvage)

Nivolumab for adjuvant high-risk UC



Pembro for *BCG* unresponsive



Partnerships

Develop partnerships with aligned organizations



Raising the bar

Raising the bar in Education and Patient care



Philippe Spiess

Genitourinary Surgical Oncologist



www.siu-j.org

Twitter: @SIUJ_Journal



TargetCancer
Foundation

Rare Cancer Day
September 30, 2021

Rare Cancer Day is an international day of awareness
that shines a light on the rare cancer community and the
unique challenges faced by rare cancer patients,
caregivers, and families.

