



TEXAS SOCIETY OF GENETIC COUNSELORS
PRESENTS THE

ANNUAL EDUCATION CONFERENCE

MAY 14TH, 2021
10:00AM-4:30PM

PROGRAM BOOK AND RESOURCE GUIDE



AGENDA

- 10:00 AM** **Welcome Remarks**
Damini Desai Morah, MS, CGC
Sara Mokhtary, MS, CGC
- 10:15 AM** **Keynote Lecture:**
Rethinking Imposter Syndrome
Dr. Valerie Young
- 11:45 AM** **Break**
- 12:00 PM** **Action Planning for Cultural Change in Genetic Counseling**
Dr. Liza Talusan
- 1:00 PM** **TSGC DEI Initiatives**
Carla McGruder, MS, CGC
Haley Streff, MS, CGC
- 1:15 PM** **Lunch Break**
- 1:45 PM** **Grant Winners**
Megan Morand, MS, CGC
Sayoni Lahiri, MS, CGC
- 2:05 PM** **CMS Update**
Dan Riconda, MS, CGC
- 2:15 PM** **Networking with Fellow TSGC Members**
- 2:45 PM** **COVID-19 Panel**
Elise Watson, MS, CGC
Abigail Yesso, BS
Katie Shields, BS
- 3:45 PM** **Closing Remarks**
- 4:00 PM** **TSGC Business Meeting and Licensure Update**
- 4:30 PM** **Adjourn**

ON DEMAND CONTENT

The links to the following pre-recorded presentations are accessible via
www.tsgc.org/virtual-aec.

To receive CEUs, evaluations must be completed by **Monday, June 14**.
Our speakers did a phenomenal job with this format - we hope you enjoy the content!

Incidental Germline Findings in Solid Tumor Profiles: Basic, Intermediate, and Advanced Cases

Kara Bui, MS, CGC

Pharmacogenetics: Another Tool in the Genetic Counselor Toolbox

Dr. Gillian Bell & Rachel Mills, MS, CGC

Meet Me at the Crossroads: The Intersection of Genetics and Fetal Intervention

Samantha Stover, MS, CGC

Cardiac Genetic Counseling for the Non-Cardiac GC

Lindsay Meyers, MS, LCGC & Laila Andoni, MS, CGC

**WE ARE EXTREMELY THANKFUL TO OUR
GENEROUS SPONSORS FOR SUPPORTING
THIS CONFERENCE AND THE TSGC!**

Genome Level



Exome Level



Panel Level



SNP Level



PUZZLE TO PRIZES

Complete the following to be entered into our raffle of five \$50 Amazon giftcards! Email the filled out PDF or answers to **texasGCaec@gmail.com** by EOD on Monday, May 17. Happy Puzzle-ing!

1. Alexion Pharmaceuticals Inc. develops therapies for what genetic condition?
2. Ambry Genetics can increase sensitivity and clarity with what test?
3. Amicus Therapeutics is committed to improving the lives of patients and families affected by what category of diseases? R
4. What is the turnaround time for Baylor Genetics' rapid whole exome sequencing (WES) test? Days
5. Blueprint Genetics offers financial assistance for families earning up to 600% of what level? (hint: QR code!) D P
6. What is the name of Foundation Medicine's CDx test?
7. Fulgent Genetics has FDA authorized testing for what disease? -
8. GeneDx's Xpress tests provide what type of result within 7 days? B
9. Invitae is the largest contributor to what public variant database?
10. Ipsen improves patients' lives through medicines in what disease specialty (Hint: includes cerebral palsy, spasticity, cervical dystonia, and hemifacial spasms.) S
11. What is the new type of result now available with MaterniT® 21 PLUS, offered by Labcorp? C
12. Myriad Genetics' myChoice® CDx is for patients with what cancer type?
13. What is the name of Natera's single-gene NIPS test?
14. Perkin Elmer Genomics offers a highly specialized assay for FSHD (Facioscapulohumeral muscular dystrophy), which looks at what region on chromosome 4?
15. Which of Prevention Genetics' updated panels includes 1991 genes? T S
16. What is the name of Progenity's carrier screening test?
17. What is the name of Quest Diagnostics' patient assistance program, which determines prior authorization requirements and patient coverage? R
18. Sema4's expanded carrier screening offers what type of personalized risk? D
19. Takeda champions underserved patients with what type of disorder? Storage

BONUS: **How many members are part of the TSGC?** The answer to this bonus question will be revealed during the Board of Directors meeting from 4-4:30. If you answer correctly, your name will be entered TWICE for the raffle!! 1

RAPID PGnome®

WHOLE GENOME SEQUENCING

- Starting at **\$2,990**
- Nearly all tests have a TAT of 9 days or less to preliminary or final report.

- Ideal for situations when a rapid diagnosis is needed.
- Detailed clinical notes are required.
- Options for patient only or family testing (e.g., Duo, Trio, etc.).

ALSO OFFERING: **RAPID PGxome®** Starting at **\$2,290**

PreventionGenetics has come to be recognized as a leader in providing high quality DNA analysis. Our expert staff of Geneticists and Genetic Counselors is dedicated to providing the highest level of service.

PreventionGenetics Services Provided

- Copy Number Variant (CNV) analysis included with all PGxome-based tests, including defined and custom panels.
- Structural Variant (SV) analysis included with all PGnome-based tests.
- Tests are assigned to our team of >20 PhDs and MDs. These experts interpret variants based on specialization in specific disease-based portfolios.
- All Test orders are reviewed to ensure most appropriate and cost effective option is performed.
- PreventionGenetics provides patients with sequencing and CNV tests for nearly all clinically relevant genes.



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Marshfield, Wisconsin 54449
Phone: (715) 387-0484

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Email: support@preventiongenetics.com



New Tests and Panels

- Congenital Anomalies of the Gastrointestinal Tract**
180 genes **\$1,350**
- Episodic Ataxia**
36 genes **\$1,070**
- Comprehensive Inherited Kidney Diseases**
323 genes **\$1,490**
- Monogenic Diabetes**
54 genes **\$1,090**

- Congenital Diaphragmatic Hernia**
60 genes **\$990**
- PGmito - Mitochondrial Genome Sequencing**
37 genes **\$590**
- Neonatal Respiratory Distress**
5 genes **\$930**

Updated Panels

- Neonatal Crisis Panel**
1991 genes **PRICING**
- Family - Trio \$2,490**
- Family - Duo \$2,290**
- Patient Only \$1,890**
- Inborn Errors of Immunity / Primary Immunodeficiency**
536 genes **\$1,490**
- VACTERL Association and Related Disorders**
84 genes **\$1,130**
- Disorders of Fatty Acid Oxidation (FAOD)**
33 genes **\$890**
- Nephrotic Syndrome (NS) / Focal Segmental Glomerulosclerosis (FSGS)**
72 genes **\$990**
- Cholestasis Panel**
70 genes **\$990**
- Stuttering Panel**
4 genes **\$890**
- Hereditary Cystic Kidney Disease**
43 genes **\$1,290**

- Long QT Syndrome**
18 genes **\$890**
- Organic Aciduria**
41 genes **\$930**
- Bone Fragility and Fracture**
71 genes **\$1,190**
- Skeletal Disorders and Joint Problems**
700 genes **\$1,790**
- Heterotaxy, Situs Inversus and Kartagener's Syndrome**
44 genes **\$890**
- Osteogenesis Imperfecta, Hypophosphatasia (HPP), and Inherited Hypophosphatemic Rickets Panel**
37 genes **\$960**
- Hydrocephalus**
37 genes **\$890**
- Non-Immune Hydrops Fetalis**
148 genes **\$1,240**



Counseling patients with positive NIPT results can be complicated.

Valuable insights when you need them most.

After nearly 10 years' experience with NIPT testing, we know that not all positive results are created equal, and by definition screening tests may have the risk of a false positive result.

The new Mosaicism Ratio result, only available with **MaterniT® 21 PLUS** (at no extra cost), helps differentiate between a positive result that is more likely to be a true positive, and one with an increased chance to be a false positive.¹

Mosaicism Ratio adds an additional level of clarity. Rely on Labcorp/Integrated Genetics women's health portfolio as your single-source for best-in-class screening, diagnostic testing, and all your needs across the entire pregnancy.



[Learn More](#)



Reference:

1. Rafalko et al. Impact of mosaicism ratio on positive predictive value of cfDNA screening. *Prenatal Diagnosis*, 2020.



Sara Mokhtary



Damini Desai Morah

GET TO KNOW YOUR CO-CHAIRS!

What is the CliffNotes version of your GC career?

D: I have been a GC for over 20 years and being a Regional Medical Specialist is only my second job! Cancer has been my subspecialty for all of these years. I worked as a clinical GC for over 16 years in rural west Texas.

S: I graduated from the CSU Stanislaus program in 2014. In my clinical role in Northern California, I primarily focused on hereditary cancer, but also worked part-time in prenatal and general genetics. I joined Invitae as a Clinical Science Liaison in 2018 and currently support providers in 11 states.

How long have you been a TSGC member?

D: I can't remember ever **not** being a member! Since the beginning!

S: Since February 2019, when I moved from San Francisco to Dallas! I remember attending the AEC in Houston and feeling so grateful that Texas had such a big and welcoming GC community.

Best thing about co-chairing?

D & S: Seeing it all come together as a final product after so many months of planning. We really hope you enjoy it!

Most challenging aspect of conference planning?

D & S: Finalizing the speakers/topics. The TSGC membership has so many different interests, and we wanted to make sure there was something for everyone. Also, keeping track of a trillion details and email accounts. We have five accounts between us!

One thing I wish people knew about me?

D: I am a patient-centered genetic counselor first and although I am enjoying my transition to Industry, working for a lab does not define me as a GC.

S: I definitely echo Damini's sentiment! GCs in various roles have more similarities than differences!

Unrelated to work: As a creative outlet (and stress reducer), I love Latin dancing. Join me if you're in Dallas!

What's one surprising thing you learned about each other?

D: In addition to being very detail-oriented, Sara has a very fun, creative side. She was behind the puzzle idea, as well as, the social/networking time.

S: Damini and I have a lot in common! It was great to talk about the shared challenges of our roles and being a GC in industry roles. Oh, and we both love margaritas (who doesn't?!)

What are you going to do with all your spare time after May 14?!

D: Relax on the beach in Mexico, finish watching Greys with my daughter, and play more table tennis with my son and husband.

S: Finish binge-watching "The Good Place," read on my patio (newly furnished!), and plan some travel!

Would you like to share anything with the TSGC Members?

D & S: It's SO worth it to volunteer! Don't worry about never having done something before, there is a first time for everything and it is best to jump right in!

For a little bit of extra work, you'll likely feel that you get more out of it than what you put in!

A FEW HOUSEKEEPING ITEMS

How to obtain CEUs

- Listen for and write down the attendance codes (the next page will help you keep track!)
- Go to www.tsgc.org/virtual-aec to complete your CEU evaluations (codes required) before Monday, June 14.
- Don't forget to complete your CEU evaluations for the pre-recorded content.
- Please don't ask for codes in the chat!

Minimize distractions

- Block your work calendar
- Put your phone on silent (or out of reach!)
- Close your email and any apps with notifications
- Set your workspace up for success!



Engage!

- Use the Zoom reactions
- Contribute to the virtual chatter
- Consider sharing your video (highly encouraged during our social time)



CEU TRACKING SHEET

ATTENDANCE VERIFICATION CODE	PRESENTATION	CONTACT HOURS
	KEYNOTE LECTURE: RETHINKING IMPOSTER SYNDROME <i>DR. VALERIE YOUNG</i>	1.50
	ACTION PLANNING FOR CULTURAL CHANGE IN GENETIC COUNSELING <i>DR. LIZA TALUSAN</i>	1.00
	COVID-19 PANEL <i>ELISE WATSON, MS, CGC, ABIGAIL YESSO, BS, KATHERINE SHIELDS, BS</i>	1.00
	INCIDENTAL GERMLINE FINDINGS IN SOLID TUMOR PROFILES: BASIC, INTERMEDIATE, AND ADVANCED CASES <i>KARA BUI, MS, CGC</i>	1.00
	PHARMACOGENETICS: ANOTHER TOOL IN THE GENETIC COUNSELOR TOOLBOX <i>DR. GILLIAN BELL & RACHEL MILLS, MS, CGC</i>	1.00
	MEET ME AT THE CROSSROADS: THE INTERSECTION OF GENETICS AND FETAL INTERVENTION <i>SAMANTHA STOVER, MS, CGC</i>	1.00
	CARDIAC GENETIC COUNSELING FOR THE NON-CARDIAC GC <i>LINDSAY MEYERS, MS, LCGC & LAILA ANDONI, MS, CGC</i>	1.00

Our passion for making a difference unites us.

Amicus is committed to improving the lives of patients and families affected by rare and orphan diseases.



A trusted partner in genetic testing

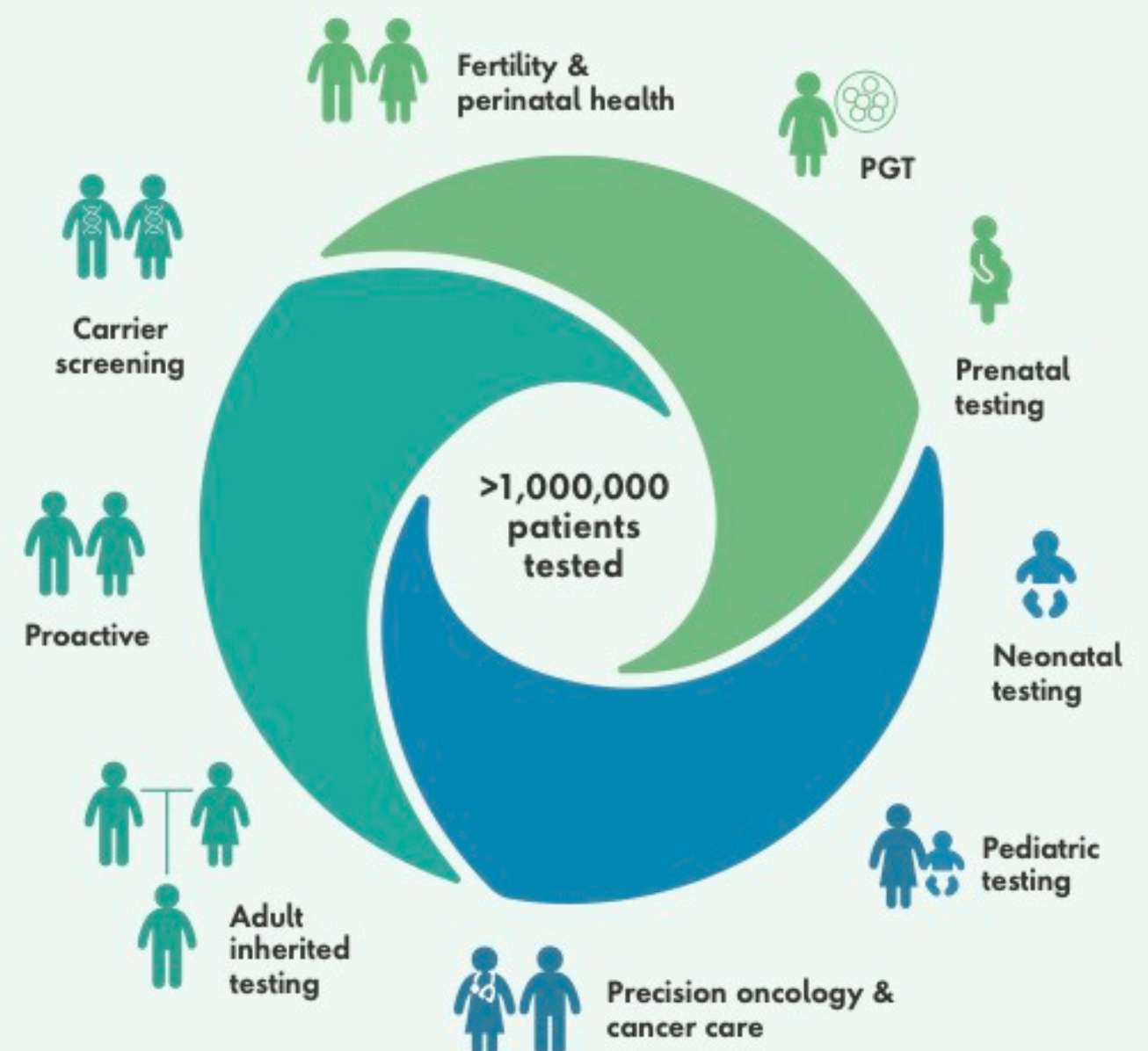
Invitae's team of medical genetics experts is dedicated to making affordable, high-quality genetic testing the standard of care in medicine.

Experience you can trust

We've tested more than

1,000,000 patients

across a broad range of indications, providing genetic information for all stages of life.



Dedicated to the highest quality

Invitae's testing is backed by peer-reviewed studies.¹

1 in 7 positive test results are challenging variants.²

- These could be missed by standard next-generation sequencing (NGS) technology.
- Invitae's customized NGS-based methods detect complex variants with high accuracy.*

Committed to transparency

Invitae is the largest contributor to ClinVar with

>390,000 submissions.[†]

SPEAKER BIOS



Dr. Valerie Young

Dr. Valerie Young is an internationally recognized expert on impostor syndrome. She is the author of the award-winning book “The Secret Thoughts of Successful Women: Why Capable People Suffer from Impostor Syndrome and How to Thrive in Spite of It” with Crown Business, now in six languages.

You can learn more about her work at impostorsyndrome.com

Dr. Liza Talusan

Dr. Liza Talusan is a highly sought after facilitator, educator, and scholar-practitioner in areas of diversity, equity, and inclusion. Currently, Dr. Talusan is a faculty member at the University of Massachusetts Boston where she teaches both masters and doctoral courses focused on leadership, equity, and justice.



RELEVANT RESOURCES

Dr. Young's Resources

Check out Dr. Young's blog for helpful articles:

<https://impostorsyndrome.com/blog/>

Want to learn more, buy her book!

<https://impostorsyndrome.com/book/overview/>

For parents:

The Gift of Failure by Jessica Lahey

For all professionals:

Mindset by Carol Dweck

NSGC DEI Resources

<https://www.nsgc.org/JEDI>

<https://www.nsgc.org/Policy-Research-and-Publications/Justice-Equity-Diversity-and-Inclusion-JEDI/DEI-FAQs>

<https://www.nsgc.org/Policy-Research-and-Publications/Justice-Equity-Diversity-and-Inclusion-JEDI/DEI-Resources>

Diversity, Equity, and Inclusion Task Force

Genetic counseling is a career that embraces diversity in knowledge and humankind, to promote education, action, and autonomy in healthcare. Despite the profession's framework in diversity, less than 10% of all genetic counselors identify as an ethnic or racial minority.

2020 Initiatives for Black and African American applicants to Texas Genetic Counseling Programs:

1. Application fee reimbursement
2. National Matching Services fee reimbursement
3. One-time stipend for admitted students



Future Directions:

1. Expand initiatives to other underrepresented minorities (URMs)
2. Obtain outside funding for sustainability
3. Increase engagement with prospective URM applicants
4. Support other DEI-related work in Texas

Hypophosphatasia (HPP) is a metabolic disorder characterized by **LOW Alkaline Phosphatase (ALP) activity**¹

Patients with HPP may experience unpredictable, devastating, and life-limiting consequences, including:¹



PREMATURE TOOTH LOSS



SHORT STATURE AND/OR UNUSUAL GAIT



MUSCLE WEAKNESS AND/OR FATIGUE



CHRONIC MUSCLE/ JOINT PAIN



SKELETAL DEFORMITIES AND/OR FRACTURES

• In adults, low ALP activity is **<40 U/L**^{2,a}

• Age- and sex-adjusted ALP reference intervals must be used in children^{3,4}

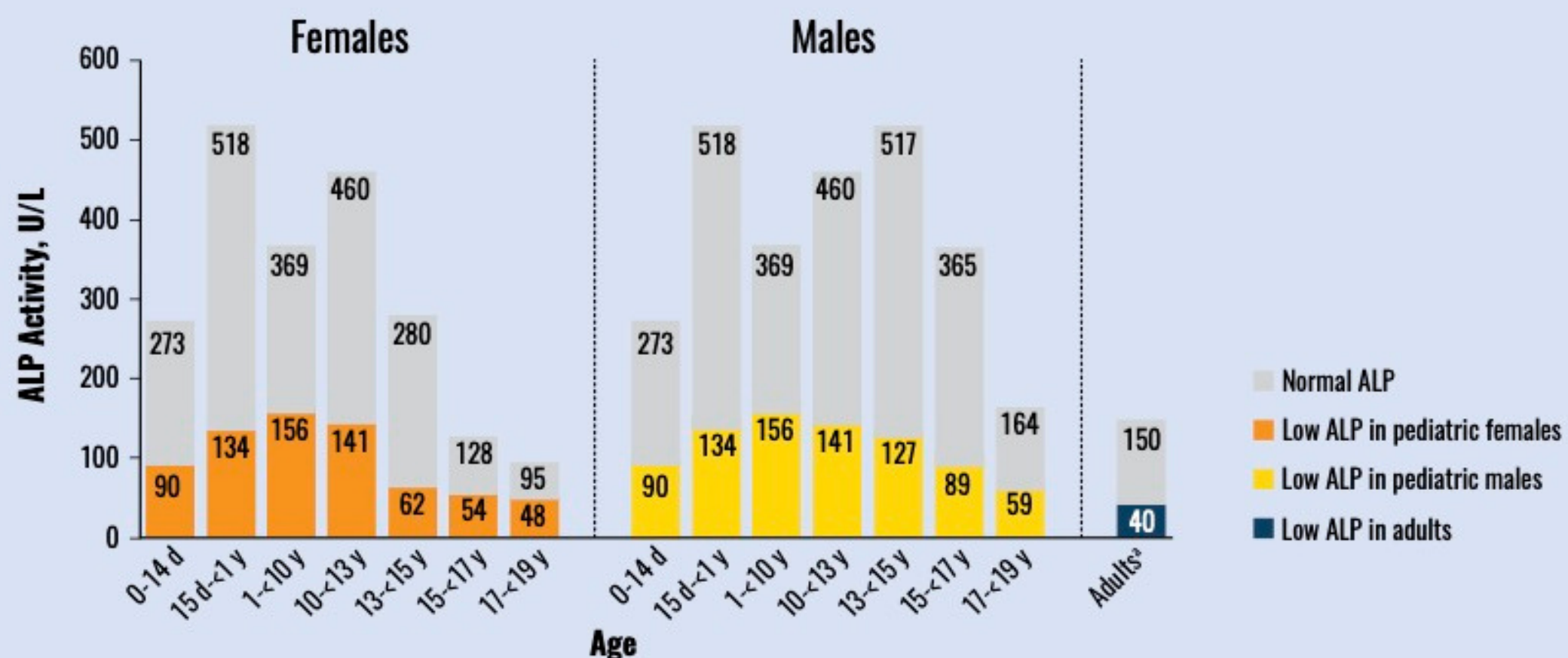
Patients with any of these key signs/symptoms and LOW ALP should be evaluated for HPP¹

^aExample cutoff from Abbott Laboratories; adult ALP ranges are lab specific and may vary.

References 1. Bishop N, et al. *Arch Dis Child*. 2016;101(6):514-515. 2. Alkaline phosphatase [package insert]. Abbott Park, IL: Abbott Laboratories; 2007. 3. Offiah AC, et al. *Pediatr Radiol*. 2019;49(1):3-22. 4. Colantonio DA, et al. *Clin Chem*. 2012;58(5):854-868.

LOW Alkaline Phosphatase (ALP) may not be flagged if your laboratory does not use age- and sex-adjusted reference intervals in children when testing ALP activity¹

Age- and sex-adjusted ALP reference ranges, U/L^{2,3}



NOTE: Graph adapted from the Canadian Laboratory Initiative on Pediatric Reference Intervals (CALIPER) project.² Caliper samples from 1072 male and 1116 female participants (newborn to 18 years) were used to calculate age- and sex-specific reference intervals. No variation in ALP based on ethnic differences was observed. Reference intervals shown were established on the Abbott ARCHITECT c8000 analyzer.

^aAdult interval provided by the Abbott ARCHITECT ALP product information sheet is for females >15 and males >20 years of age. For younger ages, Abbott does not provide lower limits of normal.³

LOW Alkaline Phosphatase (ALP) is hallmark of Hypophosphatasia.¹
To learn more, please visit www.hypophosphatasia.com

References 1. Rockman-Greenberg C. *Pediatr Endocrinol Rev*. 2013;10(2 suppl):380-388. 2. Colantonio DA, et al. *Clin Chem*. 2012;58(5):854-868. 3. Alkaline phosphatase [package insert]. Abbott Park, IL: Abbott Laboratories; 2007.

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 US/UNB-H/0095

Please contact [RAM email] to learn more information about hypophosphatasia.



PRECONCEPTION

PRENATAL

NEONATAL

PEDIATRIC

ADULT



TRUSTED TESTING for Every Patient

Whole Genome Sequencing

Includes comprehensive analysis of single nucleotide variants (SNVs), exon to chromosome level copy number variants (CNVs), *SMN1/2* copy number characterization, mitochondrial DNA, and short tandem repeat screening

CNGnome® Test

Powerful bioinformatics combined with genome sequencing technology, providing enhanced coverage of large CNVs over most traditional microarrays

FSHD Testing

Highly specialized assay to ensure an accurate repeat count of the D4Z4 region with 4q haplotyping

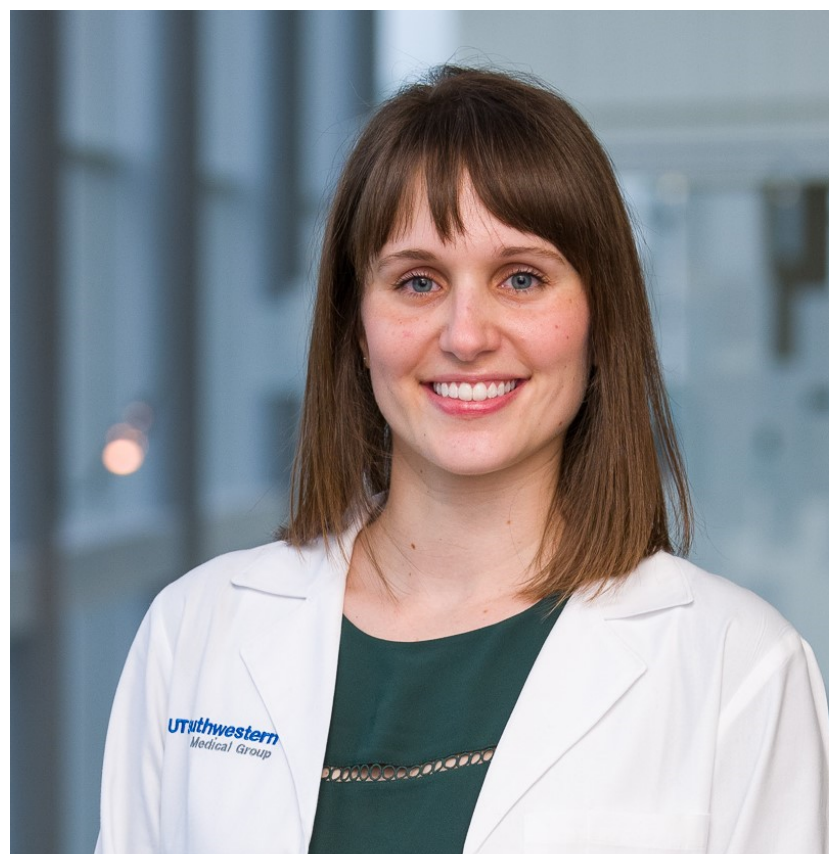
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COVID PANEL SPEAKER BIOS

Elise Watson

Elise Watson is a board-certified genetic counselor who joined UT Southwestern's Cancer Genetics department in May 2015. As part of the Cancer Genetics team, she currently sees patients at the Simmons Comprehensive Cancer Center, Texas Health Resources - Dallas, Parkland Hospital, and Moncrief Cancer Institute.



Katie Shields

Katie Shields is a 2021 graduate of the University of Texas Health Science Center at Houston's Genetic counseling program. She now works with the Medical Genetics team at McGovern Medical School at UTHealth.



Abigail Yesso

Abigail Yesso is a soon to be graduate of the genetic counseling program at Baylor College of Medicine (BCM). She is excited to begin working as a pediatric genetic counselor in a cardiac genetics clinic following her graduation in May 2021.





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For your patients, you demand precision and accuracy. For your practice, you need ease. With our Women's Health family of products, both are within reach.

From planning a family and prenatal testing to hereditary cancer screening, Natera offers high-quality genetic testing across the women's health spectrum.

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Your unified solution for
top-performing tests
in women's health

Panorama™
Next-generation NIPT

Horizon™
Advanced carrier screening

Empower™
Hereditary cancer test

Spectrum™
Preimplantation genetics

Vistara™
Single-gene NIPT

Anora™
Miscarriage test (POC)



FOUNDATIONONE®CDx

FOUNDATIONONE®LIQUID CDx

FOUNDATIONONE®HEME



ONE PROVEN PORTFOLIO OF TESTS + SERVICES THAT'S OUR FOUNDATION

Foundation Medicine's proven portfolio of tests and services offers the quality and commitment you need to help inform treatment strategies for all your advanced cancer patients. We offer tissue and blood-based testing for solid tumors, a test for integrated DNA and RNA insights, the option to include IHC for PD-L1 status with tissue testing, and decision support services — providing actionable insights for navigating cancer care.

Learn more about Foundation Medicine's proven portfolio at foundationmedicine.com/portfolio.

FoundationOne®Heme is a laboratory developed test that was developed and its performance characteristics determined by Foundation Medicine. FoundationOne Heme has not been cleared or approved by the U.S. Food and Drug Administration. For more information on FoundationOne Heme, please see its Technical Specifications at foundationmedicine.com/heme.

FoundationOne®CDx and FoundationOne®Liquid CDx are qualitative next-generation sequencing based *in vitro* diagnostic tests for advanced cancer patients with solid tumors and are for prescription use only. FoundationOne CDx utilizes FFPE tissue and analyzes 324 genes as well as genomic signatures. FoundationOne Liquid CDx analyzes 324 genes utilizing circulating cell-free DNA and is FDA-approved to report short variants in 311 genes. The tests are companion diagnostics to identify patients who may benefit from treatment with specific therapies in accordance with the therapeutic product labeling. Additional genomic findings may be reported and are not prescriptive or conclusive for labeled use of any specific therapeutic product. Use of the tests does not guarantee a patient will be matched to a treatment. A negative result does not rule out the presence of an alteration. Some patients may require a biopsy for testing with FoundationOne CDx when archival tissue is not available which may pose a risk. Patients who are tested with FoundationOne Liquid CDx and are negative for companion diagnostic mutations should be reflexed to tumor tissue testing and mutation status confirmed using an FDA-approved tumor tissue test, if feasible.

For the complete label, including companion diagnostic indications and important risk information, please visit www.FICDxLabel.com and www.FILCDxLabel.com.

SPEAKER BIOS

Kara Bui

Kara Bui has nearly two decades of experience in prenatal and cancer genetic counseling. Kara currently specializes in somatic variant annotation and is employed by Caris Life Sciences to screen solid tumor profiles for suspected germline variants. Currently, she serves as co-chair for the Journal of Genetic Counseling CEU program.



Dr. Gillian Bell

Gillian Bell is the Pharmacogenomics Service Lead at Genome Medical and Assistant Professor of Clinical Education in the Division of Practice Advancement and Clinical Education at UNC Eshelman School of Pharmacy. In addition to her current role, she serves as a member of several national and international working groups focused on implementing pharmacogenomics in clinical care.



Rachel Mills

Rachel Mills, MS, CGC is an Assistant Professor with the UNC Greensboro Genetic Counseling program where she serves as the Research and Capstone Coordinator. Rachel is currently the Vice Chair of the NSGC Education Committee. She's active in the Precision Medicine SIG and works with a group of genetic counselors to provide pharmacogenetics lectures to genetic counseling programs.



SPEAKER BIOS



Samantha Stover

Samantha Stover is a Certified Genetic Counselor and Clinical Instructor in the Department of Molecular and Human Genetics at Baylor College of Medicine. Sam is the Lead Genetic Counselor of the BCM Prenatal Genetic Counseling service Texas Children's Pavilion for Women location, as well as the TCH Fetal Center. Sam is also the second study coordinator for the BCM site of the Prenatal SEQ study.



Lindsay Meyers

Lindsay is a board certified genetic counselor with expertise in cardiovascular genetics and pediatrics. She is now a Sr. Manager for Cardiac and Pediatric Services at a telegenetics company and has interests in alternative service delivery models and expanding access to care in these areas.



Laila Andoni

Laila Andoni is a pediatric cardiology genetic counselor at Primary Children's Hospital Heart Center. In addition to clinical patient care she also teaches and supervises students for the University of Utah Graduate Program in Genetic Counseling.

SOMATIC TESTING RESOURCES

Suggested Reading

Dumbrava EL et al. Expanded Analysis of Secondary Germline Findings From Matched Tumor/Normal Sequencing Identifies Additional Clinically Significant Mutations. JCO Precis Oncol. 2019;3. PMID: 31517177

Forman A. and Sotelo J. Tumor Based Genetic Testing and Familial Cancer Risk. Cold Spring Harb Perspect Med. 2019 Sep 30. PMID: 3157038

Mandelker D., et al. Germline-focussed analysis of tumour-only sequencing: recommendations from the ESMO Precision Medicine Working Group. Annals of Oncology 30: 1221-1231, 2019. PMID: 31050713

Meric-Bernstam F. et al. Incidental germline variants in 1000 advanced cancers on a prospective somatic genomic profiling protocol Annals of Oncology 27: 795-800, 2016. PMID: 26787237

Moody E. W. et al. Comparison of Somatic and Germline Variant Interpretation in Hereditary Cancer Genes. JCO Precision Oncology 2019 :3, 1-8
<https://ascopubs.org/doi/full/10.1200/PO.19.00144>

Cosmic Database: <https://cancer.sanger.ac.uk/cosmic>

Ask a Friend

Cancer SIG Somatic Subcommittee: somaticexpertpanel@gmail.com

Learning Modules (memberships may be required):

The Jackson Laboratory: Precision Medicine for Your Practice
<https://learn.education.jax.org/browse/hpe/cme/courses/scptrcme>

NSGC Cancer SIG Somatic Subcommittee

To access Cancer SIG Webinars, go to NSGC Communities -> Cancer SIG -> Library -> Cancer SIG: Webinar Recordings or contact Tamara.Braidenyulangone.org for the recording and slides.
-3/17/21: Somatic Case Review includes a TP53 CHIP vs. mosaic case by Veronique Weinstein
-December 2020: Clonal Hematopoiesis and LFS by Megan Frone

ASCO eLearning: Reading and Interpreting Genetic and Genomic Test Reports

CARDIAC RESOURCES

Find a Cardio GC

Cardiovascular Genetic Counselor Map

<https://www.google.com/maps/d/u/0/viewer?msa=0&mid=1xJ-mj1q6l-VyBhphsoAmQeIVpSY&ll=11.243062693489742%2C-142.97607399999993&z=3>

Can link to from CV SIG homepage <https://www.nsgc.org/Members/Special-Interest-Groups-SIGs/Cardiovascular-Genetics-SIG>

NSGC Find a Genetic Counselor Tool <https://findageneticcounselor.nsgc.org/>

CHDs

Cowan & Ware 2015 Paper <https://pubmed.ncbi.nlm.nih.gov/26042910/>

The Children's Heart Foundation <https://www.childrensheartfoundation.org/about-chds/resources.html>

Little Hearts <https://www.littlehearts.org/>

22q11.2 Foundation <https://www.22q.org/>

Williams Syndrome Association <https://williams-syndrome.org/>

Noonan Syndrome Foundation <https://www.teamnoonan.org/>

Turner Syndrome Foundation <https://turnersyndromefoundation.org/>

Inherited Arrhythmias

SADs <https://www.sads.org/What-is-SADS#.YHuSthNKhfU>

Heart Rhythm Society <https://www.hrsonline.org/>

Cardiomyopathies

DCM Foundation <https://dcmfoundation.org/additional-support/>

HCM Association <https://www.4hcm.org/>

Children's Cardiomyopathy Foundation <https://www.childrenscardiomyopathy.org>

Aortopathies

Marfan Foundation <https://www.marfan.org/>

Loeys Dietz Syndrome Foundation <https://www.loeysdietz.org/>

Mended Hearts; Aortic Aneurysm Support Group <https://connect.mendedhearts.org>

John Ritter Foundation <https://www.johnritterfoundation.org/>

Familial Hypercholesterolemia

The FH Foundation <https://thefhfoundation.org/>

Lp(a) Support Group <https://familylipoproteina.org>

General

American Heart Association (guidelines) <https://www.heart.org/>

Heart Failure Society of America <https://hfsa.org/>

American College of Cardiology <https://www.acc.org>

Heart Rhythm Society <https://www.hrsonline.org/>

National Lipid Association <https://www.lipid.org/>

FETAL INTERVENTION RESOURCES

Contact Information:

Samantha Stover, MS, CGC

(832) 826-7357

srstover@texaschildrens.org

TCH Maternal Fetal Medicine and TCH Fetal Center

<https://women.texaschildrens.org/program/maternal-fetal-medicine>

<https://women.texaschildrens.org/program/texas-childrens-fetal-center>

References:

Moise KJ Jr. The history of fetal therapy. *Am J Perinatol.* 2014 Aug;31(7):557-66.

Adzick NS, et al. A randomized trial of prenatal versus postnatal repair of myelomeningocele. *N Engl J Med.* 2011 Mar 17;364(11):993-1004.

Committee opinion no. 501: Maternal-fetal intervention and fetal care centers. *Obstet Gynecol.* 2011 Aug;118(2 Pt 1):405-410.

PHARMACOGENETICS RESOURCES

How do I decide what testing platform to use?

Vo, T. T., Bell, G. C., Owusu Obeng, A., Hicks, J. K., & Dunnenberger, H. M. (2017). Pharmacogenomics Implementation: Considerations for Selecting a Reference Laboratory. *Pharmacotherapy*, 37(9), 1014-1022. <https://doi.org/10.1002/phar.1985>

Can I get some more details about counseling for PGx with specific gene/drug clinical examples?

Zierhut, H. A., Campbell, C. A., Mitchell, A. G., Lemke, A. A., Mills, R., & Bishop, J. R. (2017). Collaborative Counseling Considerations for Pharmacogenomic Tests. *Pharmacotherapy*, 37(9), 990-999. <https://doi.org/10.1002/phar.1980>

My physician colleagues are asking me about this - how should they approach PGx testing?

Mills, R., Voora, D., Peyser, B., & Haga, S. B. (2013). Delivering pharmacogenetic testing in a primary care setting. *Pharmacogenomics and personalized medicine*, 6, 105-112. <https://doi.org/10.2147/PGPM.S50598>

How can I spend another 3.5 hours learning about PGx from genetic counselors?

NSGC Online Course: "Integrating PGx Testing into Clinical Practice" <https://www.nsgc.org/Education-and-Events/Online-Education-Center/Online-Education-Inventory>



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GRANT WINNER: MEGAN MORAND



FACTORS IMPACTING ADOLESCENT AND YOUNG ADULT CANCER PATIENTS' DECISIONS TO PURSUE GENETIC COUNSELING AND TESTING

Megan Morand, MS1; Michael Roth, MD2; Susan K. Peterson, PhD, MPH2; Erica M. Bednar, MS, MPH, CGC2; Aarti Ramdaney, MS, CGC3; J. Andrew Livingston, MD, MS2; Angela Yarbrough, DNP, MSN, RN, FNP-BC2 Jessica Corredor, MS, CGC2

1 - The University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Sciences

2 -The University of Texas MD Anderson Cancer Center

3 - Department of Obstetrics, Gynecology and Reproductive Sciences, McGovern Medical School at the University of Texas Health Science Center at Houston

Introduction: Adolescent and young adult (AYA) cancer patients face a unique set of challenges when navigating cancer treatment and survivorship. Many AYAs are at risk for genetic cancer predisposition syndromes, however, motivational factors to pursue genetic counseling and genetic testing have not been described in this population. Herein, we describe AYA cancer patients' decision-making process, including motivational factors and barriers, as it relates to genetic counseling and/or testing.

Methods: Semi-structured one-on-one interviews were completed with 30 AYAs referred for genetic counseling at a large academic cancer center. Interview transcripts were coded, and data analysis was guided by grounded theory to identify major themes.

Results: Interviews were conducted with 21 AYAs who pursued genetic counseling and 9 who did not. Motivational factors identified include learning about genetic counseling as a service available to them, concern about how a hereditary cancer syndrome could affect other family members and family planning, gaining information about the need for cancer screening or prevention, affordability of genetic testing, and easing worry about additional cancer risks or cancer risk in other family members. For those who did not attend their genetic counseling appointment after referral, the following barriers emerged as themes: scheduling or other higher priorities, worry, and cost. The majority of those who did not attend their appointment expressed they would consider meeting with genetic counseling in the future.

Conclusions: AYAs at risk for genetic cancer predisposition syndromes have similar motivational factors to pursue genetic counseling compared to other patient populations, however, their younger age of diagnosis alters the lens of how these factors affect decision making. Additionally, while there are barriers limiting access to genetic counseling/testing, they did not decrease the interest in genetic testing/counseling for most patients. This leads to the necessity of genetic counseling and testing being brought up at follow up appointments after a genetic counseling referral has been declined or cancelled, to help reduce some of the barriers these patients face.

GRANT WINNER: SAYONI LAHIRI



MANAGEMENT OF GENETIC VARIANTS WITH DISCREPANT CLASSIFICATIONS: AN ASSESSMENT OF GENETIC COUNSELOR ATTITUDES AND PRACTICES

Sayoni Lahiri, Brian Reys, Julia Wunder, Sara Pirzadeh-Miller

Cancer Genetics Program, Simmons Comprehensive Cancer Center, UT Southwestern Medical Center, Dallas, TX

Introduction: Discrepant variant classifications (DVCs) arise because variant classification is not standardized across genetic testing labs posing a challenge for clinicians using genetic test results to make medical management recommendations (MMR). Currently, guidelines for reconciling DVCs for clinical care do not exist. This study examined genetic counselor (GC) attitudes and practices as they relate to the assessment and management of DVCs.

Methods: An online survey consisting of multiple-choice and free response questions was disseminated through the NSGC research listserv. Descriptive statistics were used to analyze responses.

Results: Clinical practices—The survey was completed by 229 GCs, most of whom (202/229, 88%) provide direct patient care (DPC). Most GCs providing DPC currently inform patients of DVCs (164/202, 81%) and routinely check for DVCs (176/202, 87%) with 91% (160/176, 91%) checking all variants of uncertain significance (VUSs); 48% (84/176, 48%) checking all results inconsistent with patient phenotype; and 44% (77/176, 44%) checking all positives. GCs spend an average of 42 minutes weekly range: 5–240 minutes on this task, and primarily use public databases (174/176, 99%). Personal/family history (rank 1; 57/202, 28%) and test report (rank 2; 56/202, 28%) were ranked the most important factors in determining which classification to follow. Most GCs (217/229, 95%) have not consulted the legal or ethics board at their institution about practices surrounding DVCs, but have consulted colleagues (209/229, 91%). GCs largely believe it is a clinician’s ethical duty to inform a patient of a DVC that impacts MMR (205/229, 90%) and it is not ethical to knowingly provide different MMR to patients with the same genetic variant (152/229, 66%). If two patients with the same variant had test reports with different classifications, one pathogenic and one VUS, most GCs would inform both patients of the DVC (219/229, 96%), and make the same MMR for both patients if consensus guidelines recommended risk-reducing surgery for pathogenic variants in the gene (183/229, 80%) or increased surveillance only (211/229, 92%). However, 67 of 179 GCs (37%) who stated they would make the same MMR for both patients in both scenarios also noted exceptions. Based on review of free responses, consideration of the patient’s clinical history or family history was listed as the most common exception.

Conclusions: This study shows that most GCs feel that patients should be informed of DVCs that impact management, which is echoed in current clinical practice. However, differing practices and opinions on how to manage patients with DVCs highlight the need for more professional guidance. Consulting legal or ethical experts may help GCs ensure equitable patient care.



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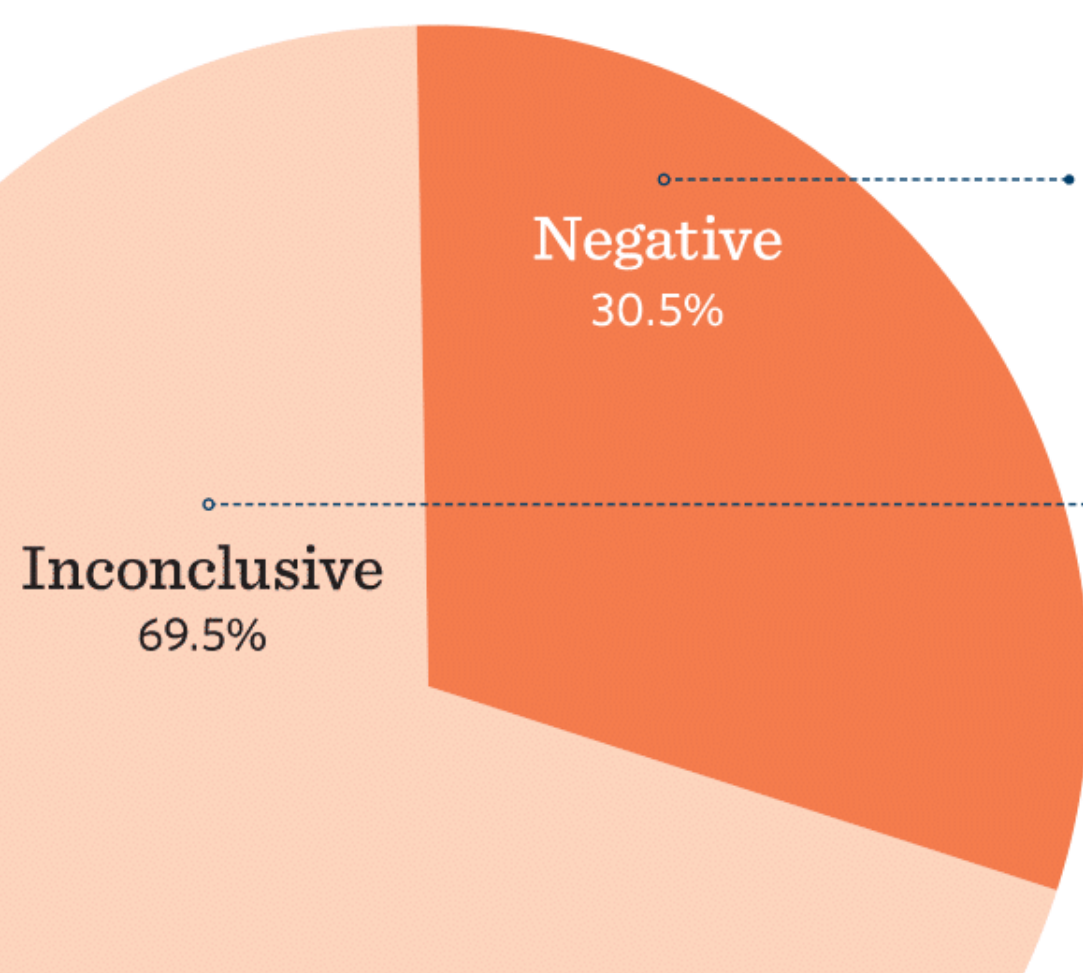
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WHAT DOES THE “ACCESS TO GENETIC COUNSELORS SERVICES ACT” DO?

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The legislation modernizes Medicare by providing Medicare status to genetic counselors allowing their services to be delivered to Medicare beneficiaries as they are for everyone else.

Access to genetic counselors is improved, as they would not practice under arcane “incident to” rules.

- Aligns Medicare policy with state licensure.
- Increases collaboration with physicians who can refer directly to genetic counselors which is often prohibited under current law.
- A physician would not be needed in the clinic for a genetic counselor to provide services to Medicare patients.

The bill would allow genetic counselors to provide services utilizing telehealth.

- Peer-reviewed studies demonstrate the efficacy of this genetic counseling delivery model.
- COVID-19 has significantly disrupted care.

Quality

Peer-reviewed research reveals that genetic counselors provide high-quality genetic services.

- Conduct extensive family history
- Ensure patients understand the benefits and limitations of genetic testing
- Select the right test
- Ensure that patients understand their genetic test results
- Personalized medicine is achieved

Reimbursement

The bill would allow payment to genetic counselors at 85% of the physician fee schedule.

- Aligns with other practitioners such as and nurse practitioners and physician assistants.
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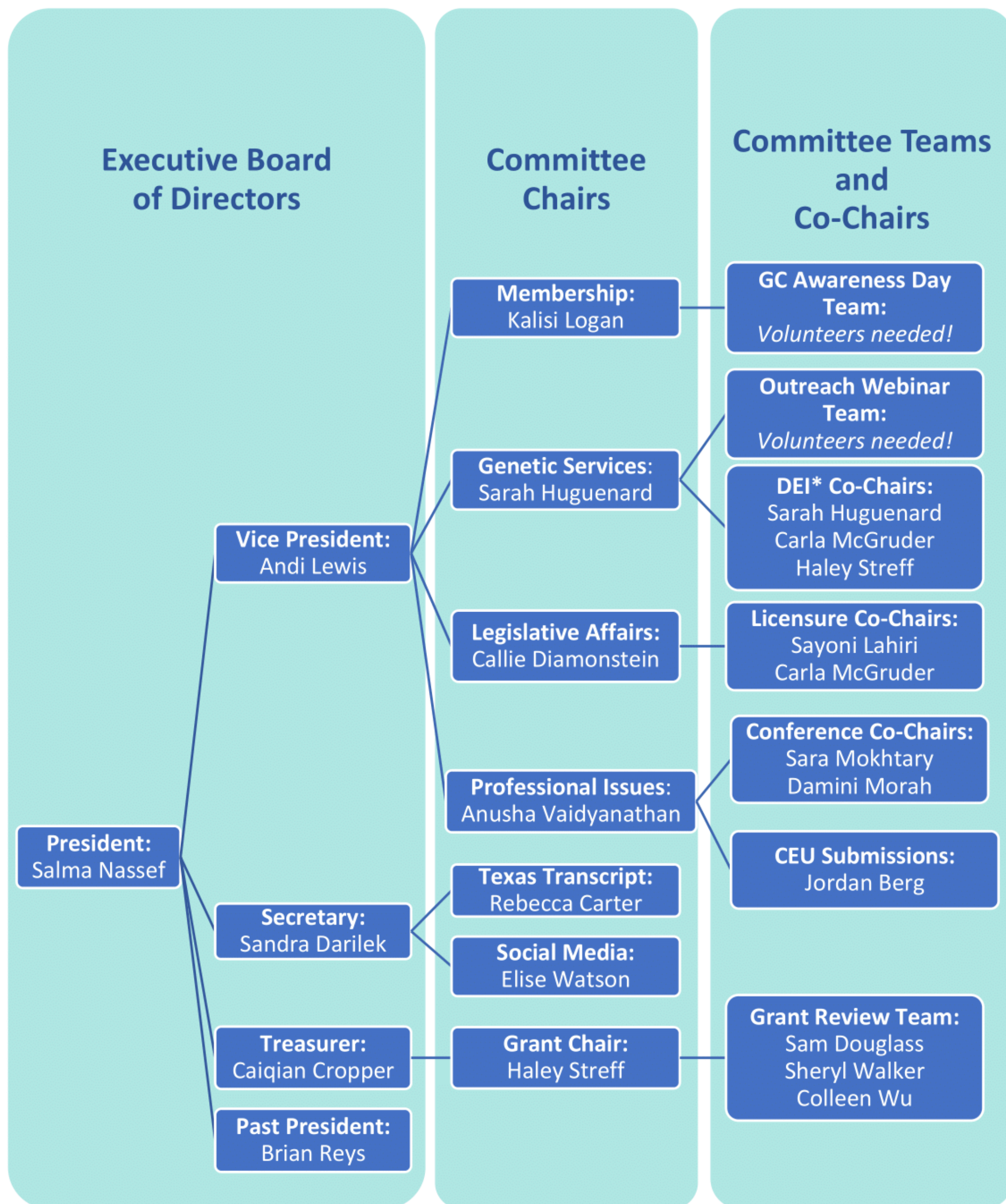
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* Diversity, Equity, and Inclusion (DEI) committee members: Jamie Fong, Damini Morah, Salma Nassef, Deanna Darnes, Farah Ladha, Jennifer Czerwinski, Georgiann Garza, Tawanna St Lewis, Sayoni Lahiri, Veena Mathur, Sam Stover, Rebecca Carter, Elise Watson, John Zimmerman, Camille Fisher, Jennifer Saucier, Rupin Dhamankar, Natalie Stoner

INTERESTED IN A TSGC LEADERSHIP POSITION?

A call for nominees will go out Fall 2021 for these positions:

Nominated members must be full TSGC members

President:

Two-year term (2021-2023)

Must have served on the Board of Directors in the past

Treasurer:

Two-year term (2021-2023)

The following Committee Chair positions will be open for self-nomination in Fall 2021. Please contact the President (Salma.Nassef@bcm.edu) if you are interested in one of these positions.

Legislative affairs: This committee identifies legislative issues that impact the practice of genetic counseling in the state of Texas, and recommend actions of the membership in relation to those issues.

Genetic services: This committee acts with respect to provision and quality assurance of clinical services provided by genetic counselors.

Professional issues: This committee selects, studies, and recommends action on any issue pertaining to the professional interest of genetic counselors.

Volunteer TODAY:

GC Awareness Day Team: Contact Membership chair: Kalisi.Logan@austin.utexas.edu

Outreach Webinar Team: Contact Genetic services chair: Sarah.Huguenard@bcm.edu

Texas Transcript Team: Contact Editor in Chief: Rebecca.D.Sample@uth.tmc.edu

Nominating Committee: Contact Vice President: Andi.Lewis@invitae.com

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TX LICENSURE UPDATE

TSGC Licensure Committee 2021 Updates

- Current Efforts- 87th Legislature Regular Session (HB 2053/ SB 557)



- **Next Steps**

- Waiting for Senate hearing and vote
- Regular session ends May 31st

- **Want to Help?**

- Check TSGC Email Blast and Social Media
 - We send info on how to contact your Representatives with scripts included
- Visit the TSGC landing page for printable resources at

<https://www.tsgc.org/members/licensure>

Email tsgc.licensure@gmail.com for more questions or to join the committee!

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