### Heartland Annual Meeting

May 24<sup>th</sup>, 2023



## Heartland Annual Virtual Meeting Agenda May 24th, 2023

Time	Topic	Presenter
8:15-8:25	Welcome and Meet the Team	Ann Chou, PhD, MPH
8:25-8:55	Heartland Project and Resource Updates	Lori Williamson Dean, MS, CGC
8:55-9:10	Heartland Last Year in Review	Barbara Jackson, PhD
9:10-9:25	NCC Updates	Megan Lyon, MPH
9:25-9:35	Break	, ,
9:35-9:50	Family Center Updates	Molly Martzke
9:50-10:05	HRSA Updates	Loraine Swanson, MPH
10:05-10:35	Social Media Updates	Denise Jirsa, MBÁ
10:35-11:15	Evaluation of Heartland's Video set about Genetics	Carson Smith, MS LCGC
	for Spanish Speakers	Bethany Johnson, MS
11:15-12:00	Exploration of Using a Spanish Chatbot or Assessing	Sophie Griffith, MS
	Cancer Risks in a Latino Population	Mackenzie Maher, MS
12:00-12:25	Demographics and Language Needs of Guardians	Elizabeth McDonald Blume, MGC
	Caring for Patients with Hemoglobinopathies in Nebraska	
12:25-12:30		Ann Chou, PhD, MPH
12.23-12.30	Adjourn	Allii Cilou, Pilo, IVIPI

#### Meet our Team











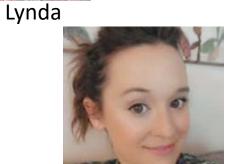












Erin









Gene

**Emily** 

# Heartland Resource Update Lori



# Heartland Last Year in Review Barb



#### NCC Updates





Since 2013, Megan Lyon has worked at the American College of Medical Genetics and Genomics (ACMG). In her current role as the Co-Project Director of the National Coordinating Center for the Regional Genetics Networks (NCC), she supports collaboration and activities between the NCC and seven RGNs, which helps foster access to quality genetic services for underserved populations. Ms. Lyon is passionate about improving the national healthcare system through policy and infrastructure initiatives. From The George Washington University in Washington, DC, she received a Masters of Public Health in Health Policy and a Bachelors of Arts in Psychology and Political Science.



#### Break Time ©



#### Family Center Updates



**Molly Martzke** 

Molly Martzke brings passion and real-life experience to her role with the National Genetics Education and Family Support Center where she serves as the Senior Program Manager. Molly has extensive experience working with diverse groups from local to international in providing family leadership training. She has dedicated her life's work to improving the experiences and outcomes of all families with children with special healthcare needs. Molly is committed to actively engaging families as equal partners in their child's health care and ensuring that the family voice is represented throughout the family's journey and within their system of care. She believes that this change happens at the system level when there is diverse representation and honest dialogue amongst all parties.



#### HRSA Updates



**Loraine Swanson** 

**Loraine** is a public health analyst with the Genetics Services Branch of the Maternal and Child Health Bureau. She has extensive experience in designing, implementing, and evaluating child wellness programs and systems change initiatives at the local, state, and federal levels.

Prior to joining MCHB in 2022, Swanson led three MCHB-funded National Technical Assistance Centers and worked in two state health departments, most recently as the Deputy Director for Child Health for the Tennessee Department of Health, where she was responsible for the leadership, operational oversight, and evaluation of the state's Early Childhood; Children and Youth with Special Health Care Needs (CYSHCN); and Perinatal, Infant and Newborn Care Sections.

Swanson began her career as an early interventionist, providing family-based therapy to children from birth to age three with developmental disabilities and has had wonderful opportunities to positively influence child health throughout her career. Interesting fact: She was the first full time parent consultant hired by a state health department for the CYSHCN Program (in Wisconsin back in 2000!).



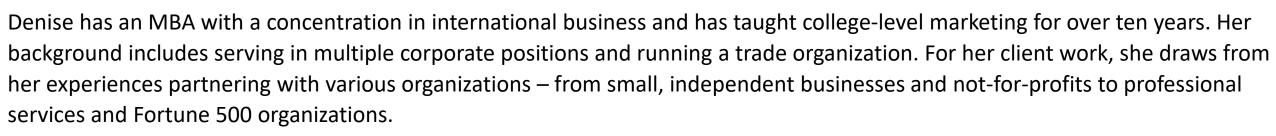
#### Social Media Updates



#### Denise Jirsa Digital Strategist

Denise is a Digital Strategist at Exclaim. She works closely with clients and the Exclaim team to create engaging and user-friendly marketing strategies that build awareness and drive conversions across social media channels, email campaigns, content marketing initiatives, and other digital marketing channels.

Her passion lies in bringing ideas to life, measuring their performance through metrics, and improving the user experience. She also enjoys collaborating with team members and strongly believes that multiple perspectives enhance the outcomes of the team's efforts.



In her spare time, Denise is a beekeeper (along with her husband) and enjoys gifting honey to friends, co-workers, and family.

For more information, visit Denise's LinkedIn profile at: https://www.linkedin.com/in/denisekotowiczjirsa/



## Evaluation of Heartland's Video set about Genetics for Spanish Speakers



**Carson Smith** 



**Bethany Johnson** 

Carson is a clinical genetic counselor at the University of Miami with an emphasis in research through the Undiagnosed Diseases Network. She received her Master of Science degree in 2022 from the University of Arkansas for Medical Sciences (UAMS) where she collaborated with Heartland to satisfy the requirements of her thesis project. Today she is presenting the results from this research.

Bethany Johnson graduated from the University of Arkansas for Medical Sciences last week with her Master of Science in Genetic Counseling. During her time at UAMS, she was a student worker for Heartland and was able to complete her master's thesis as a continuation to Carson's previous work. She is originally from Yuma, Arizona and was interested in finding a project that encompassed her experiences and background and was able to join this project which was able to capture her interests and help in continuing the great work being done by Heartland. She will be starting a position as a cancer genetic counselor at Norton Cancer Institute in Louisville, Kentucky this coming July.

## Exploration of Using a Spanish Chatbot or Assessing Cancer Risks in a Latino Population



**Mackenzie Maher** 

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**Sophie Griffith** 

Mackenzie is a recent graduate of the Master of Science in Genetic Counseling Program at the University of Oklahoma Health Sciences Center. She will be starting a prenatal genetic counseling job later this year at MN Health Fairview in Minneapolis, MN.

Sophie is a recent graduate of the Master of Science in Genetic Counseling Program at the University of Oklahoma Health Sciences Center. She works as a certified genetic counselor for Kaiser Permanente Mid-Atlantic States. Her areas of interest include equitable genetic counseling service delivery, cancer genetic counseling, and prenatal genetic counseling. She resides in Washington, D.C. with her partner Michael.



**Elizabeth McDonald Blume** 

Elizabeth McDonald Blume (she/her) graduated in May 2023 with a Master of Genetic Counseling (MGC) degree from the University of Nebraska Medical Center (UNMC). She obtained a Bachelor of Science degree from Buena Vista University in biology and psychology in 2007. She worked for the Iowa Newborn Screening Program (INSP) from 2008 to 2021 as a Clinical Laboratory Technical Specialist, serving as the hemoglobinopathies lead analyst. She was a part of several pilot screening endeavors for INSP, including succinylacetone screening for Tyrosinemia type 1, severe combined immunodeficiency (SCID), and spinal muscular atrophy (SMA). She and her partner, David, are returning to Des Moines, IA in June 2023 where she will pursue genetic counseling career opportunities. Her professional interests include improving health literacy, advocacy for patients with genetic disorders, and legislation to enhance access to genetic counselors. In her spare time, she enjoys spending time with her dog and cat, traveling, reading, and consuming as many podcasts and documentaries as possible.



### Adjourn











