

RedHott Project

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WARRIOR UNIVERSITY

Warrior University is an online, curriculum-based educational platform, powered by the patients and caregivers of the Sickle Cell Consortium. All current classes, presentations and workshops are classified into four warrior university pillars:

- Disease Education This pillar focuses on existing sickle cell disease education. Classes will include courses and workshops as part of the Expert Patient Series. Advances level courses will require completion of prerequisite courses (or prerequisite exemption approval).
- Community-Based Organization/Certified Advocate Training & Best Practices This pilliar encompases classes and workshops designed to provide training in expert advocacy and non-profit best practices. Courses include public speaking, grant writing, fundraising, etc.
- Research, Legislation & Policy This pillar contains courses designed to keep sickle cell patients and caregivers up-to-date on the legislative and administrative policies of importance to the sickle cell community.
- Life Skills This pillar will include courses designed to ensure that rare disease patients have the knowledge and skill set to live their best life.

REDHOTT PROJECT WEBINAR SERIES: OVERVIEW

The Sickle Cell Consortium is excited to present the RedHott Project Webinar series as part of *Warrior University*. The RedHott Project Webinar series was developed to educate individuals on the foundation for important blood transfusion terminology, how to avoid blood transfusion complications, and the critical need for increasing minority blood donations.

This series of Blood Transfusions: What You Need to Know and Do learning sessions delivered via online webinar, has been designed to provide a basic body of knowledge related to Sickle Cell Disease (SCD). Sickle Cell Disease is a chronic condition that causes red blood cells to form a sickle shape. These *sickled* cells block blood vessels and confine oxygen delivery throughout the body. This can cause people with SCD to suffer from organ failure and chronic pain crises. Blood transfusions are an important therapy for people suffering from the effects of SCD – but repeated transfusions can have harmful risks.

Curriculum Webinar Series: RedHott

Blood Transfusions: What You Need to Know and Do

The learning sessions in Blood Transfusions: What You Need to Know and Do are designed with a basic understanding of SCD. These sessions will help attendees learn how to take the hands-on knowledge gained and use it to make rational and informed decisions on whether to receive blood transfusions or decline until another time.

Session 1: Blood Transfusions: How, Why, and When?

- Understand the real risks and benefits of being transfused.
- Understand the important complications of blood transfusion.
- Be able to list the medical history that should be tracked with each blood transfusion.
- State why they should keep track of every transfusion: When, Where, Why, and How much?

February 25, 2019| 6:30 PM EST | REGISTER |

Instructors Dr. Jim Eckman, Dr. Raymona Lawrence, & Ashley Singleton

Session 2: Keeping it Safe: Blood Matching

This session will focus on the participants learning how to keep detailed records of their transfusion history, comprehending the potential hazards and benefits, and how to prevent and treat medical issues related to blood transfusions.

- Describe their role in preventing blood transfusion complications.
- Understand why they need to follow instructions for treating complications.

February 27, 2019| 6:30 PM EST | REGISTER |

Instructors Dr. Jim Eckman, Dr. Raymona Lawrence, & Ashley Singleton

Session 3: Keeping it Safe: Iron Overload

This session will focus on the participants learning about serious blood transfusion complications and their effect on the body, as well as being able to provide an accurate account of their history with blood transfusions.

- Describe iron overload and alloimmunization as blood transfusion complications.
- State methods to prevent iron overload and alloimmunization.

March 4, 2019| 6:30 PM EST | <u>REGISTER</u> |

Instructors Dr. Jim Eckman, Dr. Raymona Lawrence, & Ashley Singleton

Session 4: African-American Blood Donations: Why are they important?

This session will focus on the participants learning the significance of minority blood donations and how to access education on effective procedures to increase minorities to donate blood.

- Explain the importance of minority blood donations.
- Access best practices to increase minority blood donations.

March 6, 2019 | 6:30 PM EST | REGISTER |

Instructors Dr. Jim Eckman, Dr. Raymona Lawrence, & Ashley Singleton

Session 5:Let's Talk: Patient-Provider Communication

This session will focus on the participants learning to discern and advocate their needs when it comes to conveying to medical staff regarding transfusion requirements.

- Differentiate when a transfusion is necessary and when it is not necessary.
- Effectively communicate with medical providers about blood transfusion related needs.

March 11, 2019| 6:30 PM EST | REGISTER

Instructors Dr. Jim Eckman, Dr. Raymona Lawrence, & Ashley Singleton



James Eckman, MD, is Emeritus Professor of the Department of Hematology and Medical Oncology and held appointments as Professor of Medicine and Adjunct Professor of Pediatrics in Medical Genetics at Emory University School of Medicine. He was committed to establishing a sickle cell program at Grady Memorial Hospital, and after intensive state lobbying for funding in 1984, became Medical Director of the world's first 24-hour comprehensive acute care sickle cell center.

Dr. Eckman's other interest is in public health services for individuals with genetic diseases. He has championed newborn screening for sickle cell disease on a local and national level. His work has saved the lives of many sickle cell children who would have died from pneumococcal sepsis if timely preventive care with oral penicillin prophylaxis was not started. It was through his efforts that Georgia instituted universal mandatory sickle cell screening for newborns in October of 1998. He serves as a member of several local and national committees and acts as an advocate to continue awareness and support of these programs.



Raymona H. Lawrence, DrPH, MPH, MCHES is an Associate Professor of Community Health in the Jiann Ping Hsu College of Public Health at Georgia Southern University. Her research focus is community engagement in rural, marginalized populations-especially those with Sickle Cell Disease. Dr. Lawrence is currently a dual principal investigator on a \$9.7 million Patient Centered Outcomes Research Institute (PCORI) cooperative agreement entitled, *Comparative effectiveness of peer mentoring versus structured education based transition programming for the management of*

care transitions in emerging adults with sickle cell disease. Dr. Lawrence also serves as the Director of Research for the Sickle Cell Community Consortium.



Ashley Singleton, M.P.H., B.S., is a research associate II at the Georgia Health Policy Center. Her areas of expertise include adolescent sexual and reproductive health, strategic planning, and program evaluation.

Singleton's current projects include work with the <u>Center of Excellence for Children's</u> <u>Behavioral Health</u> to provide fidelity monitoring and workforce development for <u>High Fidelity Wraparound</u> initiatives in the state. She also assists with coordinating a program, funded by the Centers for Disease Control and Prevention, that focuses on characterizing the complications associated with therapeutic blood transfusions for <u>hemoglobinopathies</u>.