



SPRING 2019 COURSE CATALOG

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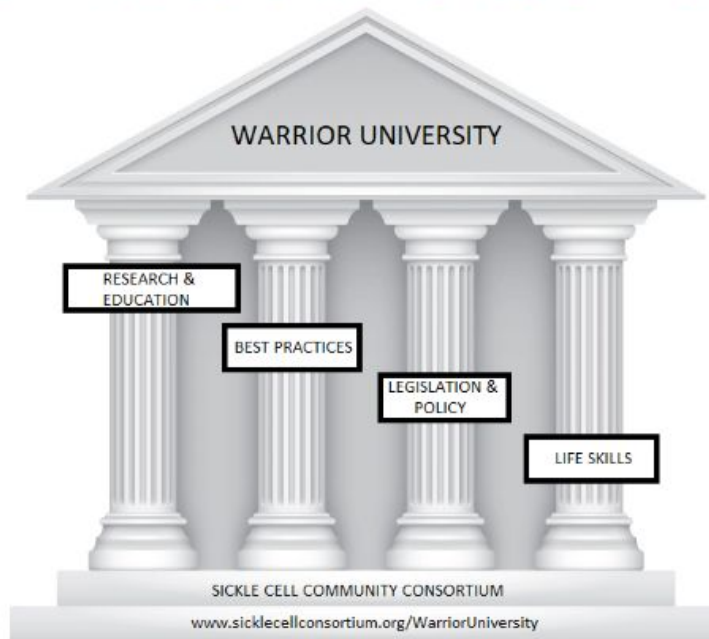
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WARRIOR UNIVERSITY

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 pillar encompasses 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.

FOUR PILLARS OF WARRIOR UNIVERSITY



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.

Sickle Cell Consortium and REdHHoTT Present: The Warrior University Online Series

Blood Transfusions: What You Need to Know and Do

Join us for an online presentation followed by a conversation with leading experts.

To learn more about Warrior University and to register for the free online series, visit

<https://sicklecellconsortium.org/warrioruniversity>

All sessions will begin at 6:30 p.m.

- February 25 Blood Transfusions: How, Why, and When?
- February 27 Keeping it Safe: Blood Matching
- March 4 Keeping it Safe: Iron Overload
- March 6 Session 4: African-American Blood Donations: Why are they important?
- March 11 Session 5: Let's Talk: Patient-Provider Communication

Presenters include:

James Eckman, M.D., Emory University
Raymona Lawrence, D.P.H., Georgia Southern University
Ashley Singleton, M.P.H., Georgia Health Policy Center



REdHHoTT is the Registry and Education for Hemoglobinopathies and Hemovigilance/Transfusion Therapy in Georgia

Blood Transfusions: What You Need to Know and Do

The learning series 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?

February 25, 2019| 6:30 PM EST | [REGISTER](#) | Dr. Jim Eckman

- 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?

Session 2: Keeping it Safe: Blood Matching

February 27, 2019| 6:30 PM EST | [REGISTER](#) | Dr. Jim Eckman

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.

Session 3: Keeping it Safe: Iron Overload

March 4, 2019| 6:30 PM EST | [REGISTER](#) | Dr. Jim Eckman

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.

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

March 6, 2019 | 6:30 PM EST | [REGISTER](#) | Ashley Singleton

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.

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

March 11, 2019| 6:30 PM EST | [REGISTER](#) | Dr. Raymona Lawrence

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.

GRANT WRITING TRAINING INTENSIVE

Session 1: Introduction to Private Foundation/Philanthropic Grant Writing

Dr. Chic Smith | March 18 | Leadership Summit

- Locating Private/Philanthropic Grant Resources
- Identifying partnerships
- Grant cycles

Session 2: The VDC (Vision, Design, Capacity) Workshop – Improving the Skills of Technical Writers

Funmi Makinde, MPH, CHES | Elton Naswood | March 19 | Leadership Summit

The VDC (Vision, Design and Capacity) Workshops have been conducted in a variety of communities across the United States since 2002. The workshops have improved the writing skills of participants and increased their understanding of the components and usual requirements of completing successful grant applications. The trainings were initially offered to community-based organizations and have since expanded to address research funding at institutions of higher education in the United States.

- Participants are sequentially engaged through lectures and interactive exercises, over 2 days.
- Review principles of technical writing, practice strategies to relay information in grant applications
- Share the tips and standards Grant Reviewers use as they screen applications going to the Funder.

Session 3: Navigating Online Grant Portals

Dr. Lakiea Bailey | March 19 | Leadership Summit

A review of online pharmaceutical grant portals

- Step by step review of submitting funding proposals via online portals
- Creating successful RFFs (Request for Funds)

FDA Patient Engagement Series: OVERVIEW

The Sickle Cell Consortium is excited to present the [Course Name] Webinar series as part of *Warrior University*. This Webinar series was developed to provide an in-depth understanding of the process for sickle cell patients, caregivers, and community-based organizations to become involved with, and influence the decisions of, the US Federal Food and Drug Administration. Together with Global Blood Therapeutics, we will provide the foundation for broadening patient/caregiver engagement.

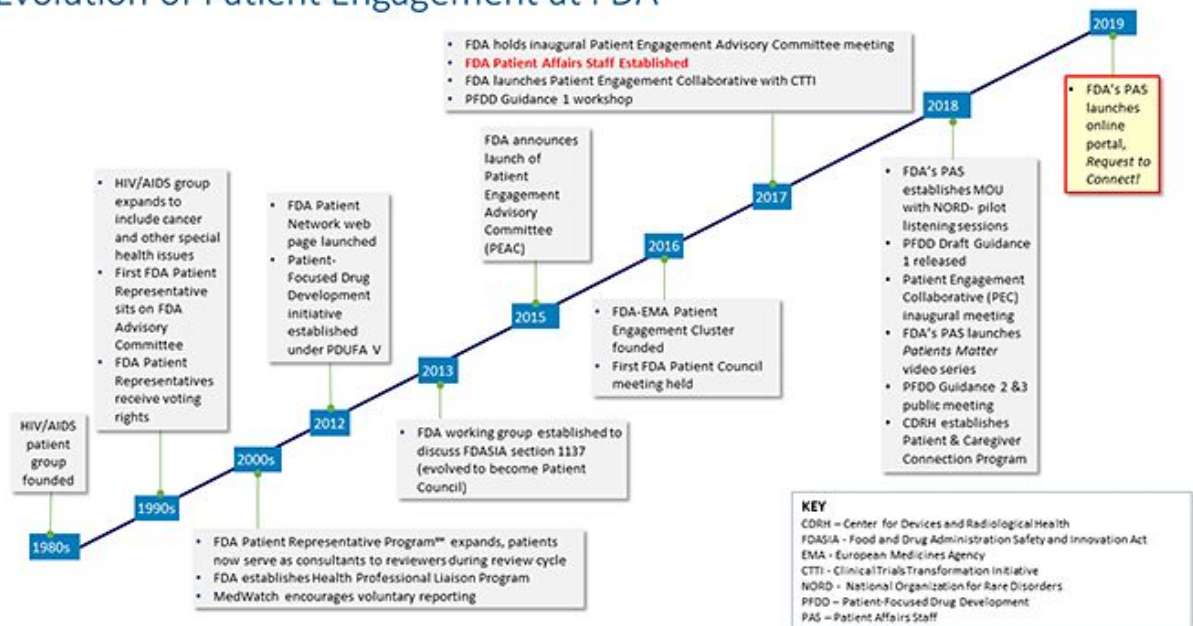
Rationale

The FDA has a difficult task when it comes to evaluating and approving new and innovative medical products.

Individual patients may experience the effects of diseases and therapies differently and each individual patient has a unique perspective about treatments or diagnostic procedures that differ from those perspectives of other patients or of their healthcare provider. The FDA has included the patient perspective in FDA Advisory Committee meetings since 1991.

Patients and Caregivers can get involved with the FDA in multiple ways. To learn more visit [here](#).

Evolution of Patient Engagement at FDA



FDA Patient Engagement Series

The learning sessions in FDA Patient Engagement Series are designed to promote patient and caregiver engagement with the FDA. With a basic understanding of FDA engagement, these sessions will help attendees learn how to take the hands-on knowledge gained and use it to become involved with the FDA Patient Engagement Collaborate, the FDA Patient Council, serve on FDA Patient Panels, and more.



SESSION 1: Why Get Involved with the FDA?

April 2, 2019 | 7 PM EST | [REGISTER](#) | Mr. James Valentine

- Regular and sustained patient advocacy with the FDA is important because:
 - Helps FDA understand the impact of sickle cell
 - Used in the approval decisions to balance benefits and risks of new therapies
 - FDA wants and solicits patient input into their processes.

SESSION 2: Developing and Advocacy Resume

April 9, 2019 | 7 PM EST | [REGISTER](#) | Dr. Lakiea Bailey

- What is an advocacy resume?
- Why is it important to build an advocacy resume?
- How to create an advocacy resume?

SESSION 3: How to get involved with FDA?

April 16, 2019 | 7 PM EST | [REGISTER](#) | Mr. James Valentine

- There are many ways the FDA solicits input from patients including product specific and context setting opportunities.
- Key ways to get involved include: acting as a patient representative, participating in listening sessions and focus group sessions.
- Helpful tips make it easier to take next steps and engage with the FDA.

GENE EDITING, VECTORS, AND SICKLE CELL DISEASE

This class is part one of a continuing webinar series (coming Fall 2019) on Gene Editing and Gene Therapy. Class one with Dr. Julie Kanter focuses on gene editing, vectors, and an explanation of the HIV comment made during the 60 Minutes interview on sickle cell disease.

THE TRUTH ABOUT GENE EDITING

Julie Kanter, MD



**Wed, Apr 24, 2019
6:30 pm**



**GENE EDITING, VECTORS, AND
SICKLE CELL DISEASE**

SAY WHAT?!

A discussion on Gene Editing,
vectors, and an explanation of the
HIV comment from the 60 Minutes
interview on sickle cell disease.

Login: www.tinyurl.com/Kanter-GeneEdit

PRESENTERS



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 [Center of Excellence for Children's Behavioral Health](#) to provide fidelity monitoring and workforce development for [High Fidelity Wraparound](#) 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 [hemoglobinopathies](#).



James Valentine, JD assists medical product industry and patient advocacy organization clients in a wide range of regulatory matters, including new drug and biologic development and approval issues. Mr. Valentine also works with clients on clinical trials operations and compliance matters.

Before joining the firm in 2014, Mr. Valentine worked in FDA's Office of Health and Constituent Affairs (previously Office of Special Health Issues) where he facilitated patient input in benefit-risk decision-making and served as a liaison to stakeholders on a wide range of regulatory policy issues. Mr. Valentine administered the FDA Patient Representative Program, facilitated stakeholder consultations during the reauthorization of PDUFA and MDUFA, helped launch the Patient-Focused Drug Development program, and developed the FDA Patient Network.

Mr. Valentine also worked at the Center for Drug Evaluation and Research (CDER) Office of Regulatory Policy where he coordinated the implementation of the medical gases certification scheme that was established in FDASIA and handled a variety of postmarket safety issues including REMS and safety labeling changes.



Lakiea Bailey, Ph.D. is a sickle cell disease advocate, educator and research scientist. Diagnosed with sickle cell disease at age three, she has become a passionate advocate for those living with rare diseases and is committed to serving as a voice of encouragement and empowerment within the sickle cell community. Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar, was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research, the Medical College of Georgia Alumni Association Award, the Georgia Regents University Leadership Award and was inducted in the Alpha Upsilon Phi honor society. Dr. Bailey is the Executive Director of the Sickle Cell Community Consortium, a coordinated network of sickle cell disease community-based organizations throughout the United States, a contract consultant with bluebird bio, has served on patient panels, a disease expert with Pfizer, Novartis, FDA, NHLBI and sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research.



Julie Kanter, MD is the director of the UAB Adult Sickle Cell Clinic and associate professor in the Division of Hematology and Oncology. Her clinical and research interests in sickle cell disease include improving access to care for affected individuals, and identifying and developing novel therapies for sickle cell disease, as well as enhancing horizontal care for patients with sickle cell disease. Kanter comes to UAB from the Medical University of South Carolina, where she was

director of sickle cell disease research. Kanter also co-directs the UAB Comprehensive Sickle Cell Disease Center.