

BREAKOUT SESSION



12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

OCTOBER 28-30, 2024

Clinical Track:

Expanding Care of Sickle Cell Disease Utilizing Telehealth

Tuesday, October 29
11:15 AM - 12:00 PM



Daniel Landau, MD
Medical University of South Carolina

Removing barriers to care: Telehealth and Sickle Cell Disease

Daniel Landau, MD
Medical Director
Hematology/Sickle Cell
MUSC department of
Telehealth

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

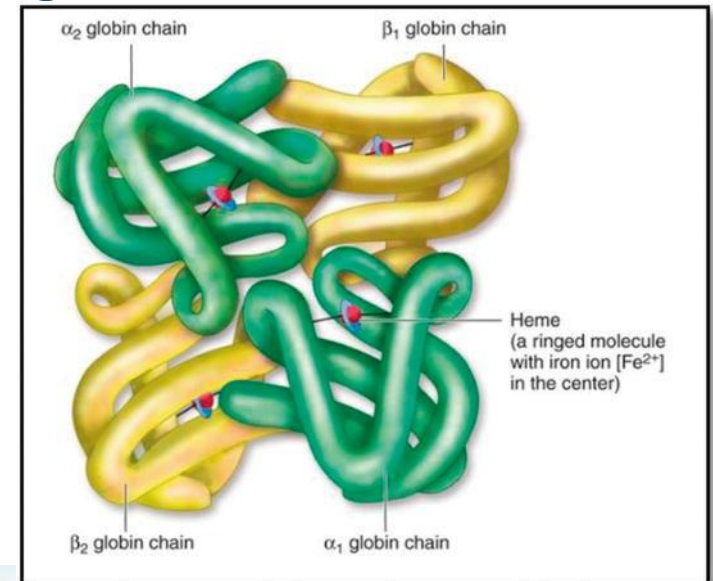
THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Understanding Sickle Cell Disease

- A common and commonly misunderstood condition
- Mutation develops from a substitution of valine glutamic acid in the beta globin chain



Understanding Sickle Cell Disease

- What is the function of red blood cells?
 - How long do they typically survive?
- The “sickled” cell has half the life span of a non sickled red blood cell (hemolysis)
- Sickled cells clump together and block blood flow to tissue and organs



Understanding Sickle Cell Disease

- Variations of the disease
 - Sickle C disease
 - Sickle Thalassemia
 - Sickle Trait
 - More

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

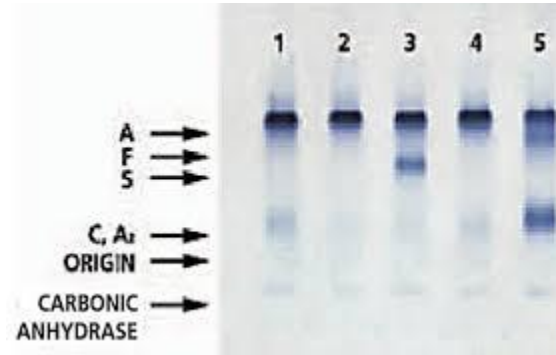
THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Understanding sickle cell disease

- How to separate out different types



How Common is Sickle Cell Disease

- 100,000+ in the US
20 million + worldwide
- 1/13 African American births have trait
- 1/365 African American births have disease
 - In the US, the African American population is the most commonly affected but sickle cell disease can be seen across many different ethnicities
- Life span is 20 years shorter than the general population

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



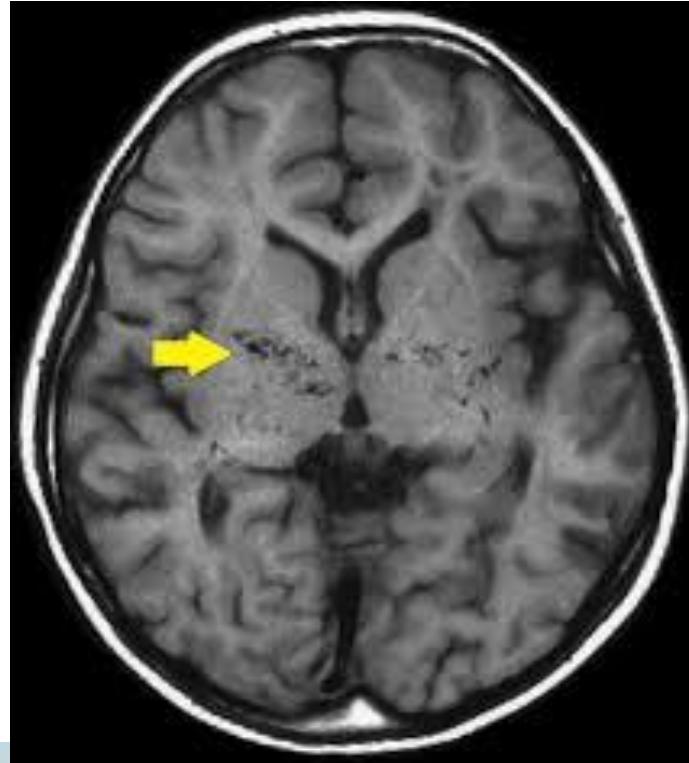
MEDICAL TECHNOLOGY

Understanding Sickle Cell Disease

- Every organ system is impacted by this disease
 - Neurologic
 - Ocular
 - Heart
 - Lungs
 - Spleen
 - Blood vessels
 - Kidneys
 - Muscles
 - Joints



Moya Moya



Stroke

- 10% + of children with sickle cell disease have stroke
 - Life time implications
 - Missed days of school, work, lower self esteem

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Eye exam



12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Cardiac complications

- Heart failure and pulmonary hypertension are common complications
 - Ultimately are common reasons for mortality

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

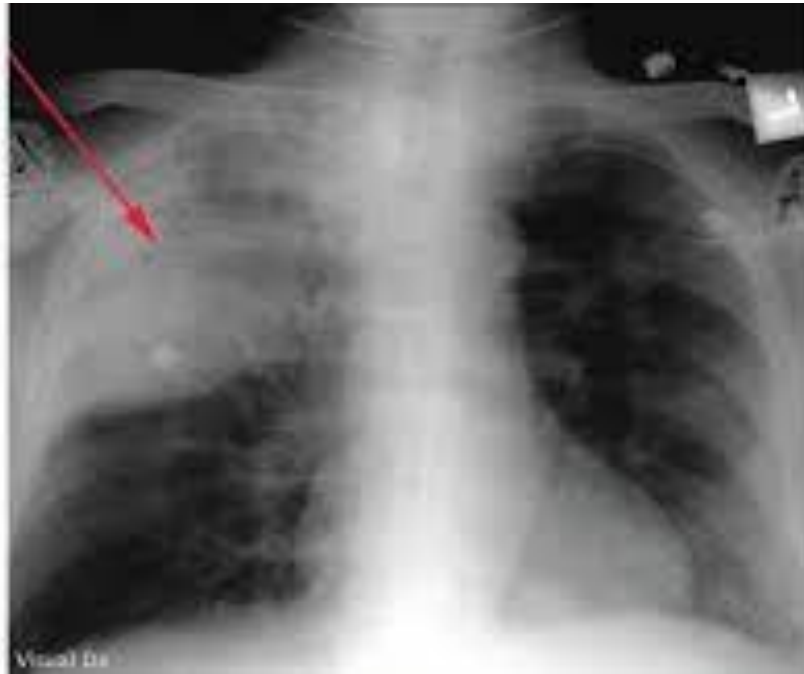
OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Acute chest syndrome



Avascular necrosis



Spleen

- Splens undergo necrosis increasing risk of infections

Rena Grant

- Director of Legislation to the House Ways and Means Committee / South Carolina House of Representatives
- Double majored in Political Science and History at Furman University in Greenville, SC and would go on to serve as Director of the director of legislation for the South Carolina House Ways and Means Committee.
- Rena played a pivotal role in raising awareness and advocating for better health care resources, support services and public understanding of SCD at the state level, leading to significant improvements in research, patient care and legislation.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Always believe that something wonderful is going to happen. Even with all the ups and downs, never take a day for granted. Smile, cherish the little things and remember to hug the ones you really love.



12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page: Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Challenges in care

- Pediatric to adult transition
- Frequent emergency room use
- Lengthy hospitalizations
- Complicated medications
- Fractured care models
- Expectation of survival
- Access to care

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Pediatric to adult transition

- Patients sometimes get lost
- Change in insurance
- Different type of care

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Emergency room use

- Severe pain doesn't always occur during office hours!
- Many centers do not have the ability to offer regular fluids or pain medications

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Lengthy hospital stays

- We have little control in how long a crisis will occur, we can only offer supportive care

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Expectations of survival

- Researchers found that the average life expectancy for publicly insured individuals with SCD was 52.6 years, with male life expectancy at birth (49.3 years) being significantly lower than that of females at birth (55 years).

Research investment

	Individuals Impacted in the US	Number of Centers in the US
Sickle Cell Disease	100,000	98
Cystic Fibrosis	40,000	130
Hemophilia	33,000	140

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Challenges with clinical trial enrollment

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

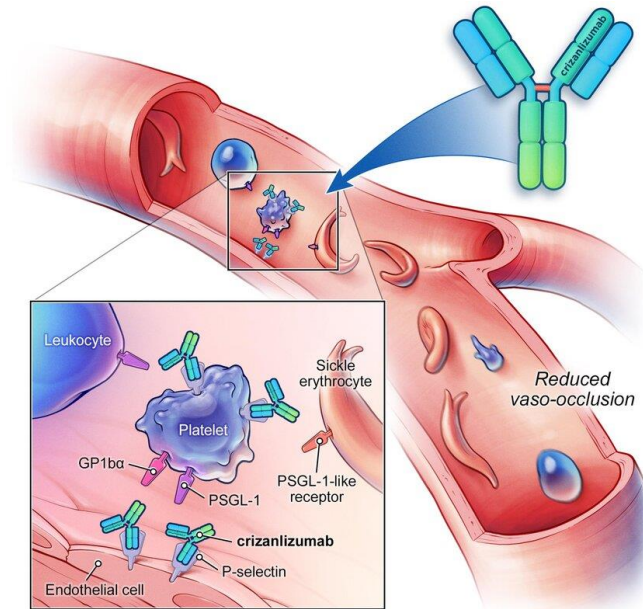
Access to care

- Many patients live outside of areas with access to specialists
- Many health care providers are unfamiliar with the complications of treatment and disease
- Higher use of emergency rooms, longer hospital stays, limited access to clinical trials
 - So many of the problems we have discussed are exacerbated by access concerns

Options for sickle cell therapy

- Hydroxyurea
 - The most important medication for sickle cell disease
- ~~Crizanlizumab~~
- ~~Voxelotor~~
- L-glutamine
- Gene editing therapy
 - \$2,000,000 per person!

Adakveo



12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

**Turning the Page:
Transformative and Digital Solutions**

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Options for treatment

- Every option has toxicities, and few patients are adequately treated
- Many therapies are also misunderstood



Expanding care via Telehealth

- 50 random charts were sampled
- Analysis included
 - Age
 - Birth gender
 - Use of Hydroxyurea
 - Completion of telehealth appointment
 - Previous relationship with hematologist within 1 year

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Expanding care via Telehealth

- Results:
 - Age: 48 (25-68)
 - Gender: 25 M / 25 F
 - Hydroxyurea use: 32%
 - Connection to telehealth: 76%
 - Greater than 40: 84%
 - Younger than 40: 61%
 - Previous relationship with a hematologist: 18%

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Basic conclusions

- Few patients have been adequately treated
- Without proper therapy, the risk of complications rises
- Without proper therapy, hospital utilization rises
- Expanding care via telehealth can address major barriers

Addressing a major barrier

- In a random review of 25 patients
 - Average distance to MUSC was 27.8 miles (1.2-96.5 miles)
 - 56% lives >20 miles away
 - 68% would need to travel more than 30 minutes to access care with hematology

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Addressing a major barrier

- Data from other papers suggests most patients won't travel more than 20 minutes for non-emergency care
- Offering an easier way to establish care could help avoid the distance barrier

Future needs

- Offering telehealth visits to larger populations
- Utilizing telehealth to improve transition from pediatric to adult care
- Addressing inpatient care/ER utilization

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

Questions?

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

*Turning the Page:
Transformative and Digital Solutions*

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA



MEDICAL TECHNOLOGY

The logo features a large, stylized number '12' in blue and green, with 'TH' in blue above it. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' in white, stacked vertically. Below this is 'OF SOUTH CAROLINA' in white. The background of the logo is a blurred image of a coastal scene with a fence and trees.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner image shows a person's hands holding a glowing blue globe with a network of lines. In the background, there are faint images of a laptop screen and a medical cross icon. The text is overlaid on this image.

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large, stylized number '12' in blue and green, with 'TH' in a smaller font to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically, followed by 'OF SOUTH CAROLINA' at the bottom.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner image shows a person's hands holding a glowing, wireframe globe. The background is a blurred scene of a person working at a computer. The text is overlaid on the right side of the image.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' in white, stacked vertically. Below this is 'OF SOUTH CAROLINA' in white. The background of the logo is a blurred image of a coastal scene with a wooden fence and a sunset.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner background is a composite image. On the left, it shows a wooden fence in front of a sunset over a body of water. On the right, it shows a person's hands holding a glowing blue globe with a network of white lines. There are also faint icons of a plus sign and a laptop in the background.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically. Below this is 'OF SOUTH CAROLINA'.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The background image shows a person's hands holding a glowing, wireframe globe. The scene is dimly lit, with a focus on the hands and the globe. There are some faint digital icons and a medical cross symbol in the background.

Turning the Page:
Transformative and Digital Solutions

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically. Below this is 'OF SOUTH CAROLINA'.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner image shows a person's hands holding a glowing blue globe with a network of white lines. The background is a blurred image of a person in a white lab coat, possibly a doctor, with a blue cross icon in the top right corner.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically. Below this is 'OF SOUTH CAROLINA'.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner background shows a person's hands holding a glowing blue globe with a network of white lines. The scene is set against a blurred background of a person working at a computer. A blue medical cross icon is visible in the top right corner.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically. Below this is 'OF SOUTH CAROLINA'.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner background shows a person's hands holding a glowing blue globe with a network of white lines. The background is a blurred image of a person in a white lab coat, possibly a doctor, with a blue cross icon in the top right corner.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large, stylized number '12' in blue and green, with 'TH' in a smaller font to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically, followed by 'OF SOUTH CAROLINA' at the bottom.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The background image shows a person's hands holding a glowing, wireframe globe. The scene is dimly lit, with a focus on the hands and the globe. In the background, there are faint outlines of a person's face and some technical equipment, suggesting a medical or technological setting.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically. Below this is 'OF SOUTH CAROLINA'.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner image shows a person's hands holding a glowing, wireframe globe. The background is a blurred scene of a person working at a computer. The text is overlaid on the image.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA

The logo features a large blue '12' with a green 'TH' to its upper right. To the right of the '12' is the text 'ANNUAL TELEHEALTH SUMMIT' stacked vertically. Below this is 'OF SOUTH CAROLINA'.

12TH
ANNUAL
TELEHEALTH
SUMMIT
OF SOUTH CAROLINA

www.palmettocareconnections.org

The banner background shows a person's hands holding a glowing blue globe with a network of white lines. The scene is set against a blurred background of a person working at a computer. A blue medical cross icon is visible in the top right corner.

***Turning the Page:
Transformative and Digital Solutions***

OCTOBER 28-30, 2024

THE WESTIN HILTON HEAD ISLAND RESORT AND SPA