Sickle Cell Warrior
Needs Across the Life Span

Wanda Whitten – Shurney MD
CEO / Medical Director
Sickle Cell Disease Association of America
Michigan Chapter
Quality of life!
Shirley Miller

Manager - Adult sickle cell program
Carolinas Healthcare System
CLINICAL TRIALS

Cell adhesion
- Rivapensil – GMI 1070 (RESET) – interfere with adhesion to selectin
- Sel G2 – interfere with adhesion to selectin
- Poloxamer 188 (EPIC) – stabilizes damaged membranes making less sticky

Inflammatory pathways
- NKTI120 – iNKT cell inhibitor
- Regadenoson – iNKT inhibitor

Upregulation of hemoglobin F
- HQK-1001 – induce fetal hemoglobin
- panibinostat

Hemoglobin polymerization and sickling
- AES-103 – binds hemoglobin to prevent polymerization
- GBT440 – increased oxygen affinity

Nutrition
- Omega 3 Fatty Acid (SCOT Trial)

Platelet activation
- DOVE – (Prasugrel) – interferes with platelet response
- Hestia - Ticagrelor – Phase II
Genetic cure for SCD in the next 5 years!

Dr. Edward Benz Jr
Executive Director

Gene Therapy & Gene Editing
The New England Journal of Medicine

Copyright, 1986, by the Massachusetts Medical Society

Volume 314
JUNE 19, 1986
Number 25

PROPHYLAXIS WITH ORAL PENICILLIN IN CHILDREN WITH SICKLE CELL ANEMIA

A Randomized Trial

Marilyn H. Gaston, M.D., Joel I. Verter, Ph.D., Gerald Woods, M.D., Charles Pegelow, M.D.,
John Kelleher, M.D., Gerald Presbury, M.D., Harold Zarkowsky, M.D., Elliott Vichinsky, M.D.,
Rathi Iyer, M.D., Jeffrey S. Lobel, M.D., Steven Diamond, M.D., C. Tate Holbrook, M.D.,
Frances M. Gill, M.D., Kim Ritchey, M.D., and John M. Falletta, M.D.,
for the Prophylactic Penicillin Study Group

Gaston et.al.
<table>
<thead>
<tr>
<th>Name</th>
<th>Type of sickle cell diseases</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SS</td>
</tr>
<tr>
<td></td>
<td>SC</td>
</tr>
<tr>
<td></td>
<td>S Thal Zero</td>
</tr>
<tr>
<td></td>
<td>S Thal Plus</td>
</tr>
</tbody>
</table>

Usual Hemoglobin Level ________________
WHAT DR. Shurney TAUGHT ME

WRITTEN BY: LaShadria B. Eric Scott
ILLUSTRATED BY: Sara Luckhardt
Donell Ivy MD, MPH

Medical Officer
Division of Services for Children with Special Needs
Maternal and Child Health Bureau - HRSA
Treatment Demonstration Grant
Increase # of physicians caring for patients with SCD
Increase # of physicians prescribing hydroxyurea

Newborn Screening Grant
Locate patients - Community Health workers
Care coordination
ABOUT REFLEXOLOGY

Reflexology is the application of pressure to areas on the feet, hands and ears. Reflexology is generally relaxing and may be an effective way to alleviate stress.

The theory behind reflexology is that these areas correspond to organs and systems of the body. Proponents believe that pressure applied to these areas affects the organs and benefits the person’s health.

Reflexologists use foot charts to guide them as they apply pressure to specific areas. Sometimes these practitioners use items, such as rubber balls, rubber bands and sticks of wood, to assist in their work. Practitioners of reflexology include chiropractors, physical therapists and massage therapists, among others.

Several studies funded by the National Cancer Institute and the National Institutes of Health indicate that reflexology may reduce pain and psychological symptoms, such as anxiety and depression, and enhance relaxation and sleep. Studies also show that reflexology may have benefits in palliative care of people with cancer.

Reflexologists claim that reflexology also can treat a wide variety of medical conditions, such as asthma, diabetes and cancer. However, scientific evidence is lacking to support these claims.

Reflexology is generally considered safe, although very vigorous pressure may cause discomfort for some people.
Type of sickle cell: ____ SS _____ SC _____ S beta thal zero _____ S beta thal plus

Other ______________________

Usual Hemoglobin level ____________________

Blood Type ______________________________

Allergies:

- Medications
- Hospitalizations
- Transfusion Hx
- Surgical Hx
- Diagnostic Studies
- Medical Appointments
Current Practice:
Managing Complications

Managing wellness:
Keeping Patients Well

Gary Gibson
Julie Cantor
June 19th is ....

World Sickle Cell Day
5 MYTHS AND FACTS ABOUT SICKLE CELL DISEASE (SCD)

1. PAIN
MYTH: All individuals with SCD are drug addicts.
FACT: The hallmark of SCD is severe unpredictable pain sometimes requiring high doses of narcotics.

2. LIFESPAN
MYTH: Individuals with SCD don’t live past the age of 21.
FACT: The vast majority of individuals live well into adulthood.

3. TRAIT
MYTH: Sickle cell trait is a mild form of sickle cell disease.
FACT: Sickle cell trait is not a disease; it is generally an asymptomatic carrier state.

- If both parents have sickle cell trait, there is a 1 in 4 chance of having a baby with SCD.

- 1 out of 13 African Americans has sickle cell trait and many don’t know that they have it.

4. RACE
MYTH: SCD only affects black people.
FACT: SCD is seen in people of many races.

5. CURE
MYTH: Bone marrow (stem cell) transplant is a universal cure.
FACT: Not all individuals with SCD are eligible for stem cell transplant. There are associated risks. To learn more about the NIH Cure Sickle Cell Initiative, visit www.curesickle.org.

ABOUT THE ARTIST
HERTZ NAZAIRE

Hertz was born in Port-Au-Prince, Haiti on October 2, 1973. The source of his love of color stems from his memories of the Taptaps, which are colorful trucks and taxis painted with murals depicting Haitian life. He studied art at the Art Institute of Fort Lauderdale and the University of Bridgeport.

Hertz struggles with the pain and challenges of sickle cell disease, which has caused his vision to fail over the years. The frustration of slowly going blind, however, has encouraged him to appreciate the process of painting with a deeper purpose. A recent series of his paintings is focused on the themes and images of the earthquake in Haiti and the life that comes after such a tragic event.

To learn more about “Naz,” visit: www.nazaire.info
• Education
• Support isolation
• Mental health
• Resources
• Compassionate care  Primary and specialized
• Transition
• Navigating the system
• Education career
• St jude school book
• Pediatric tool kit
• Understanding
• Listened to, heard
• Believed
• Respected
• Dignity and death