



METROPOLITAN SEATTLE
SickleCell
 TASKFORCE

100th Anniversary of Sickle Cell Anemia in Western Culture

Walter Clements Noel was a young, educated man who lived with his mother and father in Granada, a small island off the coast of Venezuela. The Noel family inherited their estate from Walter's mother and grew a variety of tropical agriculture crops. In 1904, Walter was sent to the United States to study dentistry in Chicago.

In December 1904, Walter went to the emergency room complaining of respiratory distress. It was here that he met his physician James B. Herrick and intern Ernest Irons. Noel's symptoms continued through dental school. Doctors Herrick and Irons followed Walter's clinical course through many hospital admissions over the next three years.

In 1907, Noel graduated and return to Barbados to open up a practice. He was

the second professionally trained dentist to practice in the capital city, St. Georges. Walter died on May, 2, 1916 at the age of 32 from pneumonia.

Herrick and Irons lost contact with Noel after his return to Granada. Three years later, in 1910 Herrick and Irons prepared their report for *Archives of Internal Medicine*. The report described peculiar elongated and sickle shaped red blood cells in case of severe anemia.

The patient they described, Walter Clement Noel, was the first case of sickle cell disease documented and recorded in Western medicine. SCD had been around for thousands of years before the case of Walter Noel. In Africa, it had been recognized for a long time as a rheumatic disease that runs in families.

Foxy Davison

Caring for Your Child During the Winter Months

Wintertime can be especially tough for children with sickle cell disease. Trying to stay away from colds and the flu is challenging, and avoiding pain episodes triggered by the cold weather can be difficult. But there are things you can do to keep kids healthy AND have fun outdoors.

When your child isn't feeling well:

Be sure to check: temperature, energy, fluid intake, irritability, and cough symptoms.

If your child has a fever – DON'T give Tylenol or Ibuprofen until talking with your provider. We don't want to cover up a potentially serious infection by treating the fever.

Follow the fever guidelines from your provider.

At OBCC, we recommend the following:

Checking any fever 99-100.9 every few hours until it comes down. If it stays in this range for over 8 hours, call your clinic.

For a fever of 101-101.9, take your child to the clinic to be seen. If it is after hours, have your provider paged or go to the emergency room. Your child may need antibiotics.

For a fever of 102 or higher, go to the Emergency Room. Your child will need IV antibiotics.

If your child has poor energy, is not drinking well, has a new cough with a fever, or a persistent cough, or you have any questions or concerns – contact your clinic right away.

Gabrielle Seibel,
 MN, MPH, ARNP

Prevent Illness

STAY WARM – just because it's cold out doesn't mean kids can't go outside to play. It just means they need to be sure to take precautions!

Bundle up when going outside. This includes mittens, hat, and warm shoes and socks in addition to a warm coat. (OBCC families – please contact Gabrielle if you need help getting any of these items!)

Take breaks – come in and warm up frequently. Something warm to drink helps. Also try some of the ideas below during break time.

"If your child is 6 years or under – remember to give penicillin twice per day."

Gabrielle Seibel,
 MN, MPH, ARNP



Christmas Party 2009

Get a Life! Living with Sickle Cell Disease

When I was 18 I could hardly wait to get out of my mother's house. I felt that Mom was too restrictive, even though I was the oldest of two I felt like a baby. My mother was protecting me because I had Sickle Cell Disease. I realized that my mother was doing the best she could but to me it was like being in prison. So here I was an 18 year old man with Sickle Cell not really knowing what it meant. The thing I did know was that I needed to get out of my mother's house.

Coincidentally two guys at the McDonald's where I worked needed another roommate so I jumped at the chance to be free. I had very little money and even less furniture, nevertheless we moved into a three bedroom apartment. I slept on the floor in a sleeping bag with only a few clothes in my closet including my McDonald's uniform. But it was like heaven to me. Seeds of doubt crept into my head, what if I get sick? What then? I could hear my grandmother's voice saying, "do the best you can, mind your manners, be honest and truthful, work hard and the Lord will take care of the rest", words to live by.

There were days that I had twinges of pain, in my joints. Sometimes I would work through the pain by focusing on my work, but there were other times that I had to take a day or so off to rest. There were also times that I would have to go to the hospital. I would drive myself to the hospital in the early days because I did not want anyone to know that I had Sickle Cell, I wanted to be just like everyone else. I chose to drink and stay out late with my friends but inevitably I would be on the verge of a Sickle Cell crisis or have a full blown Sickle Cell crisis but I would keep doing it because I wanted to be just one of the crew.

I learned so much, how to take care of myself, what it felt like when I was headed toward a Sickle Cell crisis, how I could sometimes starve off a full blown crisis. I discovered I did not need to hide and I learned the real meaning of friendship. I learned one of the McDonald's mantras "If you have time to lean you have time to clean". Those things in combination with good friends helped me through those challenging early years of discovery.

In the early years of attempting to be self sufficient I learned that I had to find a doctor that I could trust. This was due to issues that arose at hospital emergency rooms. Sometimes I would have to wait in the emergency room for hours in excruciating pain. I found Dr. Thomas close to where I worked made an appointment and met with the doctor. He told me that he knew very little about Sickle Cell Disease but was willing to learn. That was enough for me. We learned about Sickle Cell together.

Dr. Thomas taught me the value of advocating for yourself, and together we created a plan for when I needed to be hospitalized--no more extended wait times in the emergency room. Dr. Thomas continued to be my general practice doctor through the removal of my appendix\gall bladder and numerous hospitalizations. Being hospitalized gives you plenty of time to think about your life and circumstances. I remember asking Dr. Thomas about how long people with Sickle Cell Disease live. He considered the question for a few minutes and said "the resource materials say about 21 but really it's about you and how you take care of yourself, the only limitations are what you put on yourself."

To coexist with Sickle Cell Disease you must make a positive life for yourself. I recently turned 50 and here are a few things that I have learned in my years of living with Sickle Cell Disease. 1) You are not defined by Sickle Cell Disease. Sickle Cell is something that we live with but it is not who we are. 2) Create and achieve goals. Sitting around wishing that we did not have Sickle Cell Disease and brooding about it serves no purpose. You would be better served to determine what you like to do (cooking, writing, volunteering, etc.) and pursue that. 3) Get busy doing something. Get off your butt and move around (walk, swim, bike, etc.), I know it's hard to be motivated to move when you are hurting but trust me it will help in the end. Remember to breathe. Take at least 6 deep breaths an hour.

By setting goals even small ones and completing them it gives us a sense of accomplishment that is hard to come by especially if you have been sick with a Sickle Cell crisis. We all get down and get depressed but the key to rebounding successfully is to have a purpose or routine that you stick to. We are constantly inundated with reasons why people effected by Sickle Cell Disease cannot do something but there are even more things that we can do. Find one of those thing and commit yourself to it, and do it well. One of the things that having Sickle Cell has taught me is not to quit. It is frustrating to get sick even if you have been taking good care of yourself but I see it as a test of my resolve, my commitment to achieve my goals. So getting a life is one of the keys to living with Sickle Cell Disease.

Ken West

Metropolitan Sickle Cell Task Force, President

**"Sickle Cell
Is
something
that we live with
but
it is not who we
are."**

Ken West

New Community Coordinator

Welcome, Foxy Davison to our team. She comes to us from a realm of experience working as an elementary school teacher and community program developer. Foxy enjoys teaching math and reading, and spending time with her family. She is married and has two children one of which has sickle cell. She is very excited to join the team.

The community coordinator position was created to provide advocacy and support to families and individuals with sickle cell.

If you are in need of support or advocacy or simply have ideas, questions, or concerns, please contact Foxy Davison at 253-226-5578 or msscft@hotmail.com

100TH Anniversary Quarterly Calendar

JANUARY

Wed, January 13, 2010 6:00-8:00pm

Task Force Meeting: Teens, Adults

Location: 1100 Olive Way Suite 500 Seattle, WA 98101

Task Force meetings are held every 2nd Wed of each month. All are welcomed to attend.

Topic: Annual Events, planning for the walk.

Contact: Foxy Davison, 253-226-5578

Monday-January 18th

MLK March-ALL Ages 12:00-1:00pm

Location: Garfield High School, Seattle, WA

We will be participating in the in the parade in partnership with Langston Hughes to celebrate the 100th Anniversary and promote the film.

Contact: Foxy Davison, 253-226-5578

Sat, January 30th 11-1pm

Coping with Pain-All ages

Location: Odessa Brown

There will be Child Life Specialists and a Physical Therapist from Seattle Children's to teach children and teens how to use techniques "to help with pain and stress" This is a great opportunity for kids to get to do an activity together, and there will be time for parents to meet and talk with each other and share ideas. There will be snacks and a take away item for the kids. Siblings are welcome to participate. Please RSVP

Contact: Gabrielle Seibel
206-987-7232,

gabrielle.seibel@seattlechildrens.org

February

Mon, February 15th, 9:00am

Have a Heart for Kids Day: All ages

Both our nurse and community coordinator positions are funded through the state and are in threat of being cut this year due to budget changes in Olympia. Join us as we rally with the Children's Alliance in Olympia.

Contact: Foxy Davison, 253-226-5578

Wed, Feb, 17th- 6:00-8:pm

Task Force Meeting

Location: 1100 Olive Way Suite 500 Seattle, WA 98101

Topic: Film and Walk

Contact Person: Foxy Davison, 253-226-5578

Sat, February 20th - 5:00pm

GET Involved! Planning Session

Location: 1810 East Spruce Street,

Interested in helping to coordinate events through the year? Please come join us. We need your help. Dinner will be served.

Seattle

Contact: Foxy Davison, 253-226-5578

March

Mon, March 15th, 6:30-8:30pm

Pizza Night: ALL Ages

Location: Napoli Pizzeria Ristorante, 8600 14th Ave S.

Come join us for some great food, folks, and fun.

Contact: Foxy Davison, 253-226-5578

Wed, March 17th 6:00-8:00pm

Task Force Meeting- All ages

Location: 1100 Olive Way Suite 500 Seattle, WA 98101

Topic: Film and Walk

Contact: Foxy Davison, 253-226-5578



Langston Hughes and the Metropolitan Sickle Cell Task Force presents:

Nurse.Fighter.Boy.

Directed by - Charles Officer

The story of three archetypal characters, the nurturer, the warrior and the child.

JUDE is a nurse and single mother living with Sickle Cell Anemia. She works nights at the City Hospital to provide for her 12-year-old son, and dreams of returning home to Zion, (St. Elizabeth, Jamaica). SILENCE is a 'past his prime' boxer who fights illegally to survive. CIEL is a boy who delves into music, conjuring dreams for his mother. During the last week of summer, a late-night brawl finds the fighter in the nurse's care causing their three fates to be forever entwined.

April 17, 2010

7pm

Langston Hughes Black Film Festival

Opening Night

Location: TBA

www.langstonblackfilmfest.org

Proceeds will help fund advocacy, awareness and support.

Contact: Foxy Davison, 256-226-5578

Transportation Needs?
Call Foxy Davison, 253-226-5578

Washington State Patient Care Coordinator

I am a Hematology nurse. I have worked with sickle cell disease since 2000. When a position came up that is trying to improve the lives of people with sickle cell I jumped at the chance to be a part of it. This position is different than others. My job is to try to help families affected by sickle cell no matter where they are in Washington State, and what doctors they see. The goal of this position is to help you and your medical providers; it is NOT to replace them.

Several providers came together to share their expertise and support the granting of this money to improve care for their patients. Dr.

Bender, Odessa Brown Children's Clinic, Dr. Louie, Mary Bridge Children's Health Center, Drs. Richard and Hobbs, Seattle Cancer Care Alliance, Dr. Judy Felgenhauer, Sacred Heart Medical Center. I'm grateful to each of them and their dedication to improving care for patients with sickle cell. I depend on their expertise as we move forward with this program.

Right now, the best focus we can have is on prevention. Making sure every patient is up to date on necessary screening tests will identify any potential complications. I want to be sure everyone is connected to doctors they can work well with. Until we find a universal cure we have to work hard to stay ahead of sickle cell disease and the problems it can cause.



"I hope that by minimizing sickle cell disease complications you will be unencumbered so you can live up to your dreams. I look forward to working with you."

Trinna Bloomquist, R.N., B.S.N.

The Power of Zinc

Eating a balanced diet is important for everyone, especially when you have a health condition that requires special attention. You've probably heard it before, but food is *TRULY* our medicine. What we put in our mouths everyday not only tastes good and gives us energy, but it can greatly affect your long term health and ultimately make you feel strong each day.

For people who have sickle cell, there are certain nutrients you need to pay special attention to. Nutrient needs vary from person to person and it is always recommended that you discuss your specific needs with your doctor or dietitian to make sure that you eat what is best for your body.

The one nutrient that is important for everyone, especially growing children, is the mineral ZINC. There are three main reasons our body needs zinc. The first reason is that our bodies need zinc to help carry oxygen to our cells which is essential for our bodies to function well. Secondly, zinc is needed to keep our immune system strong and help us not get sick. Lastly, but perhaps the most important for growing children, zinc is needed for proper growth and sexual maturity.



So, where do you get it? Many foods have zinc, and eating a wide variety of foods will help you get zinc from different sources. Below is a list of foods high in zinc. Supplements are also an option if you are not able to get what you need from food.

Foods Sources of Zinc

Oysters (Pacific/Eastern), Wheat Germ, Lean Ground beef, Turkey (dark meat baked), Pecans, Pumpkin seeds, chicken breast (baked), Milk, Egg (whole).

Leika Suzumura

Nutritionist

Community Kitchen Coordinator

Always consult your doctor or dietitian before making any major dietary changes.

Butternut Squash with Pumpkin Seed Pesto

Pumpkin seeds are a significant source of zinc and makes for a great food to prevent becoming sick during the winter.

1 large (about 3 pounds) butternut squash, peeled and cut into ½-inch cubes, about 4 cups
2 tablespoons canola oil
½ teaspoon salt

Pumpkin Seed Pesto

½ cup raw green pumpkin seeds
1 cup loosely packed cilantro
2 cloves garlic, chopped
Juice of 1 lemon
¼ cup olive oil
¼ teaspoon salt
¼ teaspoon pepper

Preheat oven to 500° F with rack in middle position.

Preparation

Toss butternut squash with 2 tablespoons of the oil and ½ teaspoon of the salt. Arrange in a single layer on a baking pan and place in oven. Roast until golden brown on edges, 20 to 25 minutes. Remove from oven and set aside.

Meanwhile, toast pumpkin seeds in a large heavy skillet over medium heat. Keep the seeds moving with a wooden spoon or by shaking the pan back and forth over the heat until seeds are puffed and beginning to brown, 2 to 4 minutes. Transfer from pan and cool.

Pulse cooled seeds in a food processor with cilantro, garlic, lemon juice, olive oil and ¼ teaspoon each of salt and pepper till all ingredients are blended and reaches a smooth consistency.

Toss squash with pesto and salt and pepper to taste. Serve immediately.

Serves 4-6