Red Blood Cell Disorders
Quarterly Newsletter

UHN Toronto General Toronto Western Princess Margaret Toronto Rehab Spring 2018

RBCD newsletter

Adapting and Persevering

By Jermaine Anthony O'Connor

Jermaine Anthony O'Connor

> "My patience, resilience, compassion are all the things I wouldn't change for the world."

Growing up with Sickle Cell SC, I've had to navigate life not always feeling like others around me. No matter how much I wanted to be. Knowing and accepting that I will live with an illness for the rest of my life was difficult. However, it forced me to learn at how well I can adapt and persevere and most of all, it helped me develop a sense of gratitude.

Having had my spleen removed at 5 years old, and constant hospital visits, my journey has been a long one. At times I wanted to feel "normal" but felt hindered by my condition and the pain I experienced. What I had begun to learn about pain was that as excruciating as it felt, it was always temporary.

Sickle Cell made me into everything I am today, but it could never define me.

Through pain and coping, I would turn to music and begin writing poetry and journaling, then committing to working out 5 times a week as a form of therapy and emotional self-regulation. Despite my sickle cell, in 2015, I was able to graduate with a Marketing Degree from Ryerson University, and began working in the field of marketing and communications. Now I am currently pursuing continuing education to hone my skills and knowledge in digital marketing.

At 26 years of age, I still don't feel like everyone else. But I have experienced so much that I wouldn't change a thing. My patience, resilience, compassion are all things I wouldn't change for the world. To trade my pains, would be to trade my successes.

Patience is the reason why I live with such optimism, it gave me perspective. Because the means, the process, although arduous, are exactly what makes you worthy of the reward at the end of it all. I learned not to chase for endings, but to focus on now. Pain was only a process; the newfound clarity and relief, was a result of my transformation.

Striving for Success, Despite Thalassemia By Merna Hedo

Hello, I am Merna and I started my treatment at Toronto General Hospital's since 2016. I have been fighting a rare condition called thalassemia since I was a baby. It is challenging living with a disease that most people have never heard of. As a child and even now as an adult, it was always hard. Friends at school would say mean things or flinch as if I was contagious. Adults try to be more careful, but when the topic comes up, you still get the facial expressions and other non-friendly reactions.

Merna Hedo

Getting treatment around the world

I was born in Iraq and my family moved to Greece when I was two years old so that I could have access to a more specialized treatment centre in Athens. In 2013, impacted by the economic crisis in Greece, my family decided to immigrate to Canada and once again my treatment was a priority.

Canada has a great public health infrastructure and my parents and I did a lot of research to be sure it would be safe for me to come here.

It was of course stressful and scary, but that the medical teams first at The Hospital for Sick Children (SickKids) and later at the Red Blood Cell clinic at Toronto General made the transitions easier.

I had my routine treatment for as long as I could remember in Athens," she says. I had doctors I knew and trusted, so it certainly was scary to change everything and come to a new country.

But the doctors at SickKids and here were always so nice and friendly. They made this whole process a lot better.

Coping

I am a dedicated student and found ways to manage school schedules and my treatment. Losing one full day per month because of the transfusions appointments wasn't easy. I learned to teach myself in many subjects using class materials and notes from different colleagues.

I am now studying for a bachelor's degree in nursing and my dream is to bring my own contributions to research in finding a cure for thalassemia and other genetic blood disorders.

I want to become a nurse and later maybe even a doctor so that I can help find a solution. I know that many great doctors and researchers are working hard to find a cure for thalassemia, but I think when you've suffered through the disease it gives you a unique perspective to it.

William Osler Adult Sickle Cell Disease Clinic

is now up and running as of mid-March, an option for patients in that locale. Dr. Andrew Binding, *(shown in photo below)* will be the hematologists, some of you are already familiar with him. The best way for interested patients to be seen is by referral. Please ask your primary care provider or hematologist to refer you. The fax # for referral is 905-494-6620.

Dr. Andrew Binding

Welcome two new fellows to our clinic

Dr. John Aneke will be with us for two years and Dr. Stéphanie Forté will be 18 months.

Dr. John Aneke

Dr. Stéphanie Forté

FAQ – Red Blood Cell Disorders Patients

1) What happens if I have a pain episode that I can't manage from home?

- **Call** the nurse practitioners by calling 416-340-4882 and press 3 to leave a message. This voicemail is checked at least every 2 hours Monday to Friday during the hours of 8:00am to 3:00pm.
- *Please seek medical attention by seeing your family doctor or healthcare provider.*
- *Go to your nearest hospital.*

2) How would I know that my hemoglobin is low?

- *You may experience symptoms such as: low energy, dizziness, short of breath.*
- *If you are close to receiving transfusion, inform your nurse of your symptoms upon arrival at the clinic.*
- **Call** the nurse practitioners by calling 416-340-4882 and press 3 to leave a message. This voicemail is checked at least every 2 hours Monday to Friday during the hours of 8:00am to 3:00pm. Due to the volume of calls, the NP may not call you back the same day especially if the issue is not deemed urgent by the NP.
- You can also see your family doctor or healthcare provider

3) How would I know that my Port-a-cath or PICC line is infected and what should I do?

- *You will experience fever, chills, rigors, discharge or the infected area is red or swollen and painful.*
- *Go to the nearest emergency department and call the nurse practitioner line at 416-30-4882 ext. 3 to inform the team.*

4) How do I cancel or reschedule a clinic appointment?

- *To cancel or reschedule an appointment, call: the clinic at 416-340-4882, Option #1*
- *If it is related to your transfusion booking, please call 416- 340-4488.*
- *If you know you can't make it to an appointment, please phone the clinic at least 48 hours before your appointment.*
- *If you missed 2 clinic appointments in a row, your appointment will not be automatically rebooked for you, it will be up to you to phone the clinic to reschedule your appointments.*

5) How do I get a letter confirming that I attended a hospital appointment?

- *Once your appointment is complete, an administrative assistant an provide you this letter.*
- *Please request the letter upon arrival at the clinic.*
- *If your request is after 4pm, you may not receive the letter until the following day.*

6) What if I am going out of town for school/employment?

- *If you are going out of town for school or employment, please inform the clinic.*
- *You will be referred to an appropriate specialty program in your new community, unless you are able to continue with Toronto General Hospital for appointments.*
- *Inform the clinic as soon as you can about your plans so that we can make arrangements.*

7) What if I am travelling for a while?

- *Inform the clinic about your plans.*
- *You may be able to have extra blood transfusion prior to leaving.*
- Requests for letters for **travel or illness** must be communicated to the nurse practitioners by leaving a message on the NP line as noted above.
- It is recommended you give at least 5 business days' notice prior to needing the letter. The letter may or may not be done depending on the current workload if you need this sooner than 5 days' notice.
- *If a transfusion was done outside of UHN, please provide information on the type of transfusion you received and a contact person.*

8) Who can I talk to if I have any questions or concerns?

- ***Do not contact more than one member of the Red Blood Cell Clinic team for your issue or concern. This creates overlap and rework for the team.
- Any medical or medication issue needs to be first communicated to the nurse practitioners in the program by calling 416-340-4882 and press 3 to leave a message. This voicemail is checked at least every 2 hours Monday to Friday during the hours of 8:00am to 3:00pm.
- *If this is related to clinic appointments, please call Red Blood Cell Program 416-340-4882, option # 1.*
- *If this is related to blood transfusion, call medical day unit at 416-340-4488.*
- *For prescription or your physical health condition contact a Nurse Practitioner at 416-340-4882, option # 3.*
- *For Inquiries regarding housing, counseling or letter for school or work accommodation, call the social worker at 416-340-4882 ext. 2*
- *If you have a complaint, please contact Patient Relations at 416-340-4907.*

Research in RBCD Program

ACTIVE Studies	Description
ACE536-B-Thal-001	Determine the efficacy of Luspatercept, a hemoglobin-boosting agent, in adults with transfusion dependent Beta-Thalassemia.
ALXN1210-PNH-302	Determine the efficacy of a complement inhibiting drug in patients with PNH
GMI-1070	Inpatient Intravenous drug (Rivapansel) treatment of sickle cell pain crises
GBT440-031	An oral anti-sickling agent for patients with sickle cell disease
Ra Pharma	Efficacy of a complement inhibiting drug in patients with PNH
CANALI Extension Study	Treating cardiac iron overload with an antihypertensive, Amlodipine
MAFIO 2	New techniques to measure the effects of cardiac iron
PKD Registry	Natural history study of patients with Pyruvate Kinase Deficiency
PNH Registry	Natural history study of patients with Paroxysmal Nocturnal Hemoglobinuria
SC genetics	Influence of genetics on clinical outcomes in hemoglobin SC disease
CVR Study	Looking at the ability of blood vessels in the brain to open and close using MRI

UPCOMING Studies	Description
Gene Therapy in SCD	Gene therapy for Sickle Cell Disease patients using a Gamma Globin Lentivirus Vector
STRIDE-2	Bone Marrow Transplant for Sickle Cell Disease Patients with severe complications
PRESMA	Using Alyx machine to do partial manual RBC exchange
RUDAS SCD	Simple screening tests for neurological issues in sickle cell disease patients
ALXN-1210-aHUS	Determine the efficacy of a complement inhibiting drug in patients with Atypical Hemolytic Uremic Syndrome.
EPIC	Identify differences in presentation and time to diagnosis in PNH patients
PNH Vaccine	Looking at the effectiveness of vaccination in PNH patients on eculizumab
White Matter Changes in SCD	Looking for the significance of tiny strokes in the brain of sickle cell disease patients
ZFN Gene Editing Study	Gene therapy using Zinc Finger Nuclease approach in sickle cell disease patients.

Upcoming Events:

The Red blood cell forum has changed form. Instead of a yearly event, it has been changed to a series of events. There will be a peer support network on **May 26th 2018 from 2-4 pm** @ Toronto General Hospital, 1EN Room 429 (Main Library).

Patient-Staff Working Group: For the past two years, Transfused Patients and Staff in the Medical Day unit has been meeting monthly to address ways to improve services. Currently six (6) patients involved. **The next meeting will be held on April 26, 12-1pm.** If you are interested in joining contact Ina.Cherepaha-Kantorovich@uhn.ca at 416-340-4800 ext. 8618

Consider becoming a UHN Patient Partner and work with UHN leaders, clinicians, and staff in a variety of important organizational planning and decision-making activities. For more information contact Samantha McCourt at patientexperience@uhn.ca

Please Save these Dates:

1) **What:** Clinical Trials, Current and New Treatments for Sickle Cell Disease,
When: **Saturday May 12, 12-4 pm**
Where: SickKids Main Building, Main Auditorium, 1st Floor, Black Wing.
Register @ E-mail: info@sicklecellanemia.ca or http://sicklecellanemia.ca/lflf_form.php

2) **What:** 5th Annual Walk for Thalassemia,
When: **July 8, 2018, 9:30 am**
Where: Centennial Park Rd, Etobicoke,
Register @ helen.ziavras@thalassemia.ca

3) **What:** Sickle Cell Disease Conference,
When: **November 9–10, 2018**
Where: Hilton Hotel 5444 Dixie Rd.
Register @ Conference@sicklecelldisease.ca

ATTENTION

The RBCD clinic has moved to 7th floor Norman Urquhart Building. Please enter in the reception area called Thrombosis/ENT.

Upcoming Evening Clinics

The evening clinics are held bi-monthly, the next ones will be:

Tue, April 17th, 2018

Tue, June 19th, 2018

Clinic Address

585 University Avenue
Norman Urquhart Building
7th Floor, Room 700,
Toronto, Ontario
M5G 2N2

Clinic phone number
416-340-4882

Clinic fax number
416-340-4559

Clinic Hours

Monday to Friday
8a.m. – 4p.m.

The Clinic is closed Wednesdays, Weekends and on Statutory Holidays.

Evening Clinics are being held bi-monthly.

Medical Surgical Day Unit Hours

Monday to Thursday
7a.m. – 6p.m.

Friday 9a.m. – 6p.m.

Please remember to sign-up for the MyUHN portal as you will be able to receive consistent email reminders for your upcoming appointments