

Saving Type-1 Diabetic (T1D) Children in Sudan & South Sudan

Kyle Thaller May 15, 2019

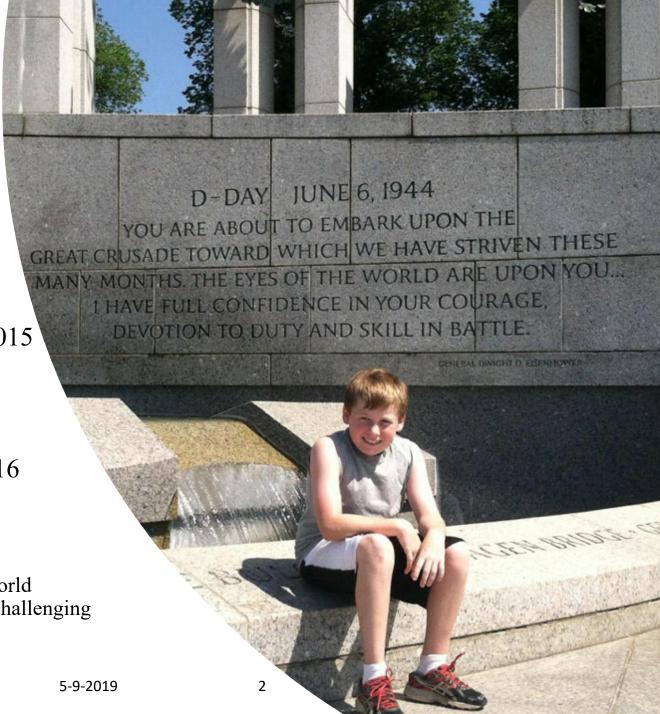
Malaria, flu, diseases mask T1D symptoms, and so the T1D child is never diagnosed . . . and 100% die.



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Who is Kyle? What is KCC? Why Sudan & S. Sudan?

- Kyle Thaller
 - o 10th grade and 16 years old
 - o Diagnosed with Type-1 Diabetes on April 27, 2015
 - Navy SEAL & Naval Academy not possible
 - Crying for days; Then inspired by S. Hawking
 - What are we without our dreams?
- Formed Kyle's Campaigns for Change (KCC) in 2016
- ❖Goal of KCC: Saving Lives By Never Giving Up
 - So.... This KCC project involves diabetes (an enormous world problem) in Sudan and South Sudan (among world's most challenging regions).



Overall Objective

Save lives and improve lifestyle of people afflicted with diabetes

• Test <u>all</u> sick children and adults in South Sudan and in rural areas of Sudan for T1D

• KCC has figured out how to do this with minimal financial support!



What is Diabetes?

Poorly or uncontrolled blood glucose

• Type-2 (T2D); Pancreas produces insulin, but cannot keep up with body's demands

o Amputations, blindness, death after decades

o Caused by lifestyle (obesity, sedentary, etc.)

• Type-1 (T1D); Immune system kills pancreas beta cells in error, and so insulin production stops

 Guaranteed death within days of full diagnosis unless treated

o Caused by genetics; Lifestyle not a factor



Type-2 Diabetes: World Pandemic

United States

- Nearly 25% of all adults in U.S. have diabetes
- 1985: 30 million people in the world have diabetes
- 2040: 650+ million people
- 80% of T2D's are in developing world where healthcare is a challenge

Africa

- 65%+ of diabetics are not even diagnosed
- T2D is worse than rest of world
- Explosive increase circa 2030 as westernized-style lifestyles evolve



Type-1 Diabetes: Silent and Guaranteed Killer

- Genetically based
 - Not related to lifestyle
 - 0.05% to .1% of population& growing exponentially
- 60-70% afflicted when 2-20 years old.
 - o Age 14 most common
- 100% fatal without treatment within 5 days once fully diagnosed
 - o Full onset in 2-12 months

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"Lost" T1D Boys (& Girls) of S. Sudan

- 1,000+ children in South Sudan and rural areas of Sudan die of T1D annually . . . without ever knowing that they have T1D
- T1D takes 2-12 months to fully present itself.
 - o Pancreas sporadically works, and then fails
 - My own personal symptoms took about 12 months
- T1D is a silent killer, and these "Lost" children will never know . . . <u>Unless</u> diagnosed.



Understanding Diabetes Sets the Stage for this KCC Project

- <u>Diagnosis is key</u> for both T1D and T2D
- Malaria, flu and other diseases can mask symptoms
- Special . . . yet simple equipment needed for diagnosis
- **❖**Test everybody who is sick





Diabetes Diagnosis and Treatment

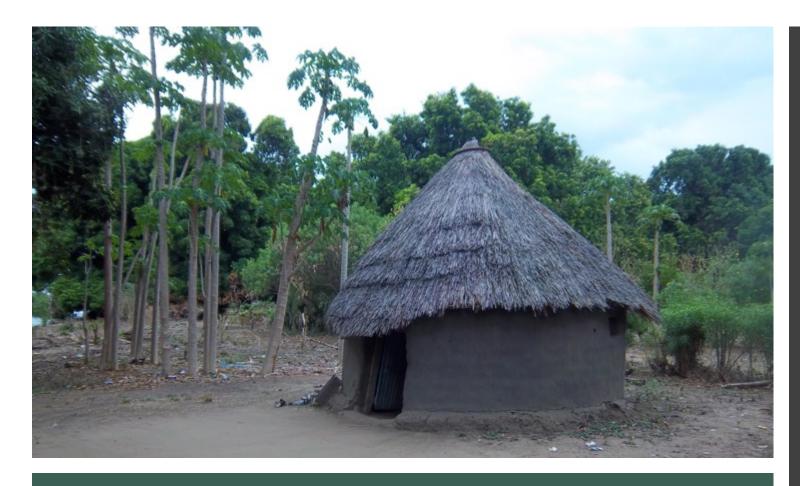
Diagnosis

- T1D and T2D diagnosis are identical.
- Glucose Monitors, Test strips & Lancets to draw blood

Treatment

- T1D (to stay alive)
 - o Insulin injections (\approx 10 times/day)
- T2D (to lengthen lifespan)
 - O Diet, exercise, loose weight, stop smoking, etc.
 - or insulin (akin to T1D)

***DIAGNOSIS IS THE KEY**



South Sudan Infrastructure is Enormously Challenging

- Three decades of civil war and conflict have left South Sudan's education systems and infrastructure devastated
 - Nearly 10 million people displaced
 - 3+ million people killed
- Country is almost 10% the size of the USA.
 - Only 200 miles of paved roads
 - One bridge over the Nile in entire country
- Healthcare nearly nonexistent



So where is the innovation? <u>Expired</u> Test Strips!

- Hundreds of millions of strips annually re-sold on the multi-billion \$\$ secondary market by hundreds of on-line firms
- Test Strips expire quickly (12-18 months)
 - Short lifespan imposed by strip manufacturers
- Typically work fine for 2-4 more years, and theoretically 10+ years post-expiration
- At failure, degradation is gradual and not dramatic.
- Once expired, test strips cannot be legally sold or resold. They are officially "worthless"
- Since key objective is to see if a person has sky-high blood glucose . . . expired test strips are ideal for initial <u>diagnosis</u>
- ❖ Since strips are "worthless, . . . KCC can/will obtain millions of expired strips. . . for <u>free!</u>



Tactical Objectives

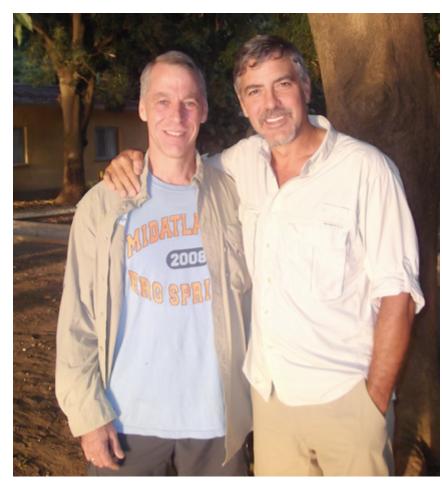
- Support T1D's and T2D's via existing clinics
 - o Malakia clinic in Juba, South Sudan
 - o Bashir Nefeidi Hospital/clinic in Khartoum, Sudan
 - o Duc Country Clinics in Jonglei State via John Dau Foundation
 - Nuba Mountains hospital
- Solicit funding and support
 - o Pharma companies in Khartoum and in USA
 - o Businessmen in Khartoum and in USA
 - Test strip manufacturers
 - o Prominent and socially motivated (impact) venture capitalists and executives
- Media Campaigns
 - Keynote speeches and presentations
 - Middle East Broadcasting Network (MBN) documentary
 - o Meetings with congressmen, ambassadors & executives
 - O Strip resellers as partners; links from other websites

Current Status

- 250,000 strips collected (valued at nominal \$100k to \$200k) in two months
- 50,000+ strips/month expected from strip resellers . . . indefinitely
- 20+ meters collected
- Media is Ramping Up
 - Keynote speech, Congressman Mtg, etc.
- Shipped 4,000+ strips into Juba April & May 2019

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Critical Next Steps



George Clooney and my Dad are long-term supporter of the people of South Sudan

Fund Raising

- > On-line and individual donors
- ➤ Corporate donors
- Funds urgently needed for airfare, etc. for Khartoum and Juba Meetings

Planning

- ➤ Meetings in Khartoum and Juba in July 2019
- ➤ Meet with key stakeholders at embassies in D.C. in Spring 2019
- ➤ Meet with other key stakeholders

Logistical

➤ Refine ability to ship into Sudan and South Sudan w/o customs issues

Medical Supplies

> Continue to obtain free strips, lancets and meters

❖ Media

- ➤ Kyle giving Key-Note at the PWCS Global Leadership Conference on May 18 (1500-2000 attendees)
- ➤ Kyle meeting with Congressman Wittman on May 17
- ➤ MBN (Middle East Broadcasting Network) doing documentary on Kyle and KCC
- ➤ Write monthly newsletter
- > Links and messaging via strip reseller websites

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How to help?

• Donate funds

o2019 Target: \$25,000

 Nearly entire effort is self-funded to date

Network and Share Ideas

o KCC.T1D@gmail.com

o Mark.thaller@gmail.com

 Join us on trip to Sudan & South Sudan in early July 2019

• Stay in touch . . . Please!











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