Patient Outreach and Messaging – A Collaborative Effort with the CDC

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Leading the Fight Against Thalassemia

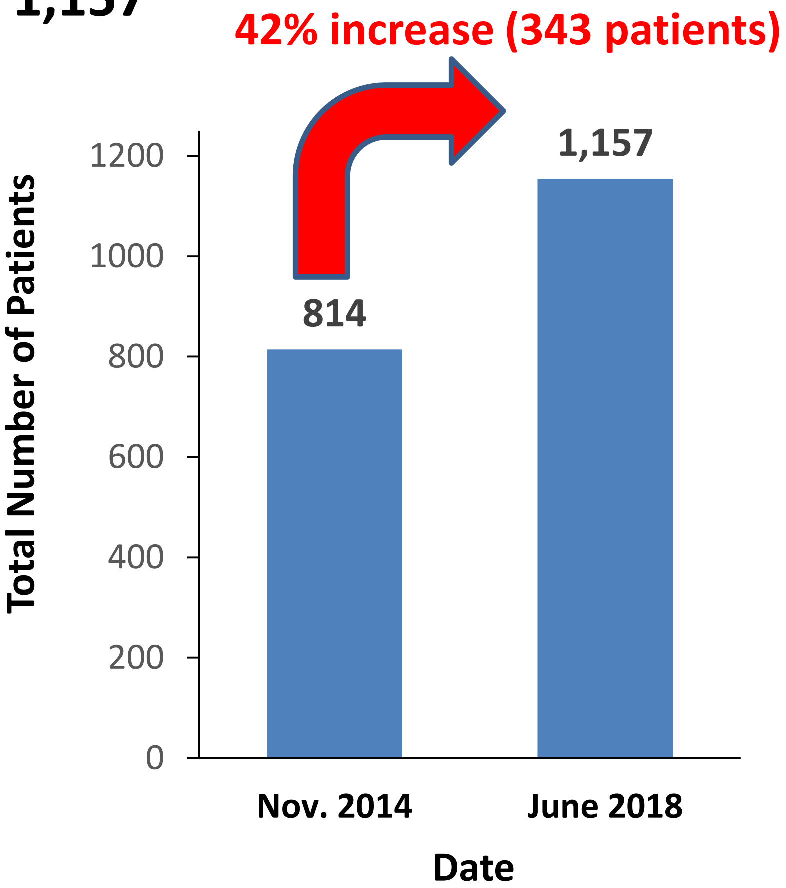
Introduction

- CAF receives grant funding and collaborative assistance from the Centers for Disease Control and Prevention (CDC) to locate additional thalassemia patients in the U.S. and to provide them with information that may improve their health outcomes
- The CDC grant supports CAF's efforts to improve patient outcomes by enabling us to:
  - (1) Identify new patients for CAF Patient Database so that education and messaging efforts will have maximum reach
  - (2) Obtain a better understanding of the size, demographics, and needs of the U.S. thalassemia patient population
  - (3) Provide patient education and health messaging aimed at decreasing preventable complications
  - (4) Increase awareness of thalassemia trait and the importance of trait testing

Objective #1: Identifying New Patients for the CAF Patient Database

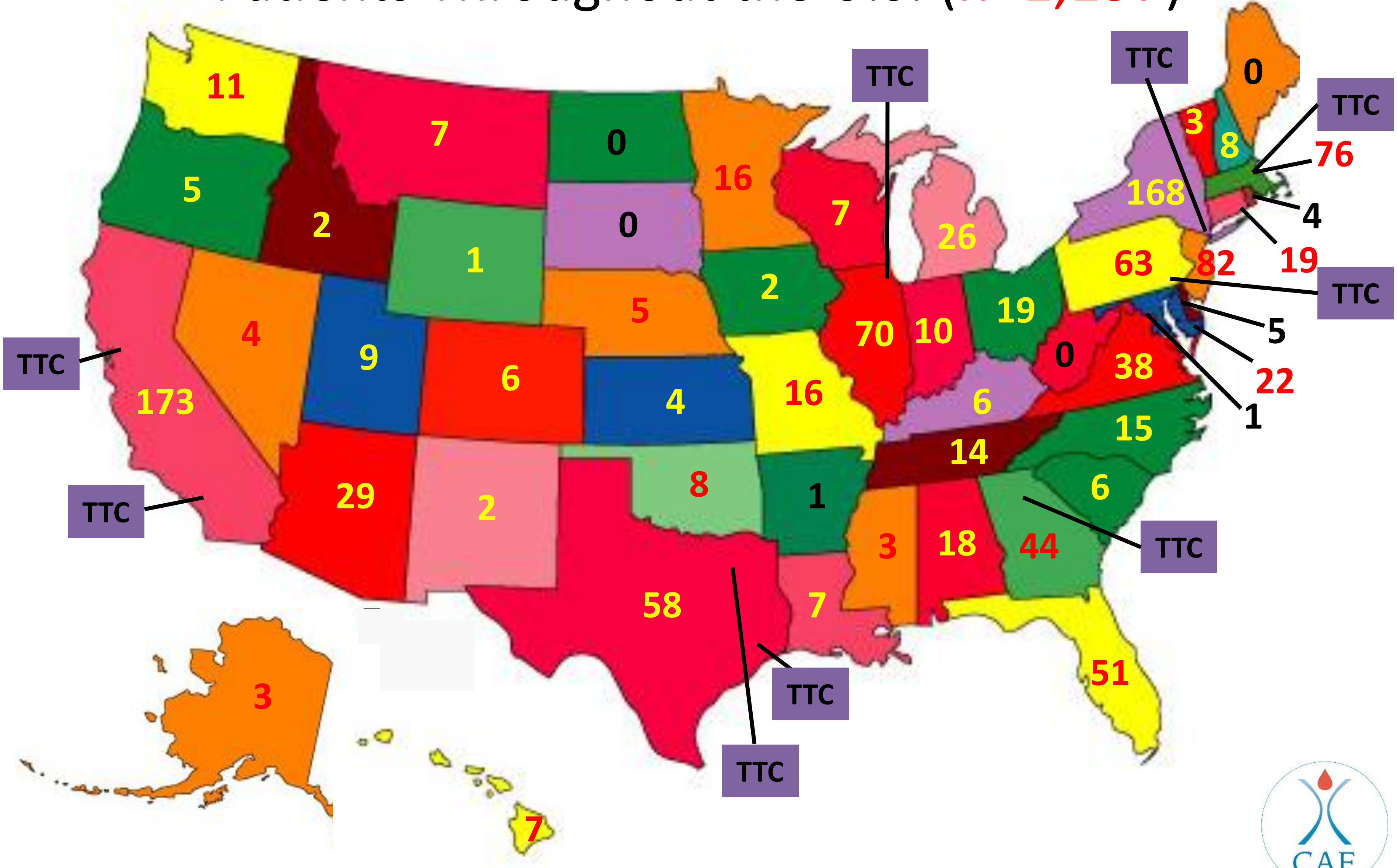
CAF Has Increased the Number of Patients in the CAF Database by 42% in 3.5 Years

- Total number of patients in CAF Database:
  - Nov. 2014: **814**
  - June 2018: **1,157**



On average, 100 patients have been added to the CAF Database each year for the last 3.5 years

Current Geographical Distribution of Thalassemia Patients Throughout the U.S. (n=1,157)



TC: Indicates one of the 7 sites originally funded by the CDC

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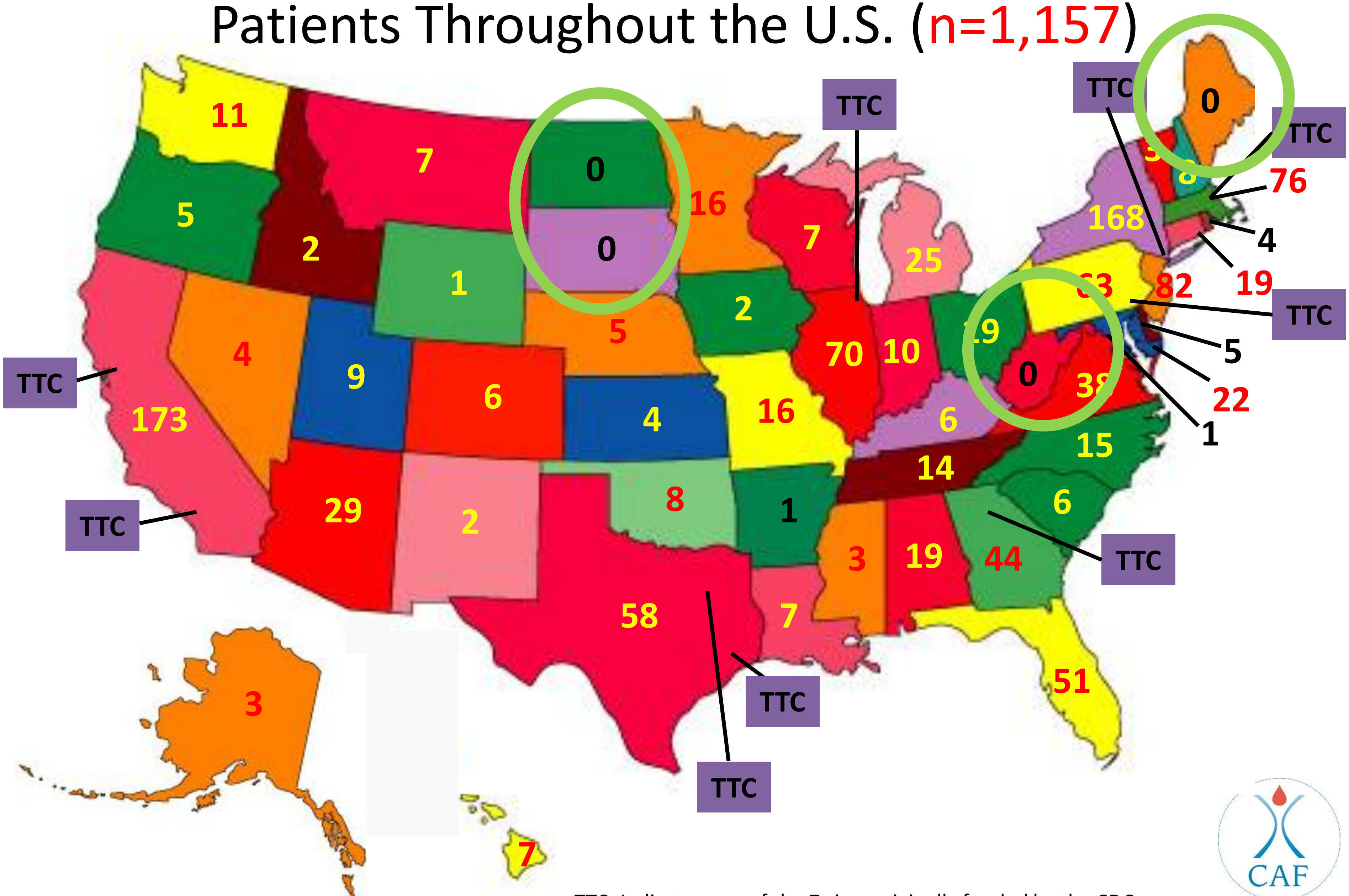

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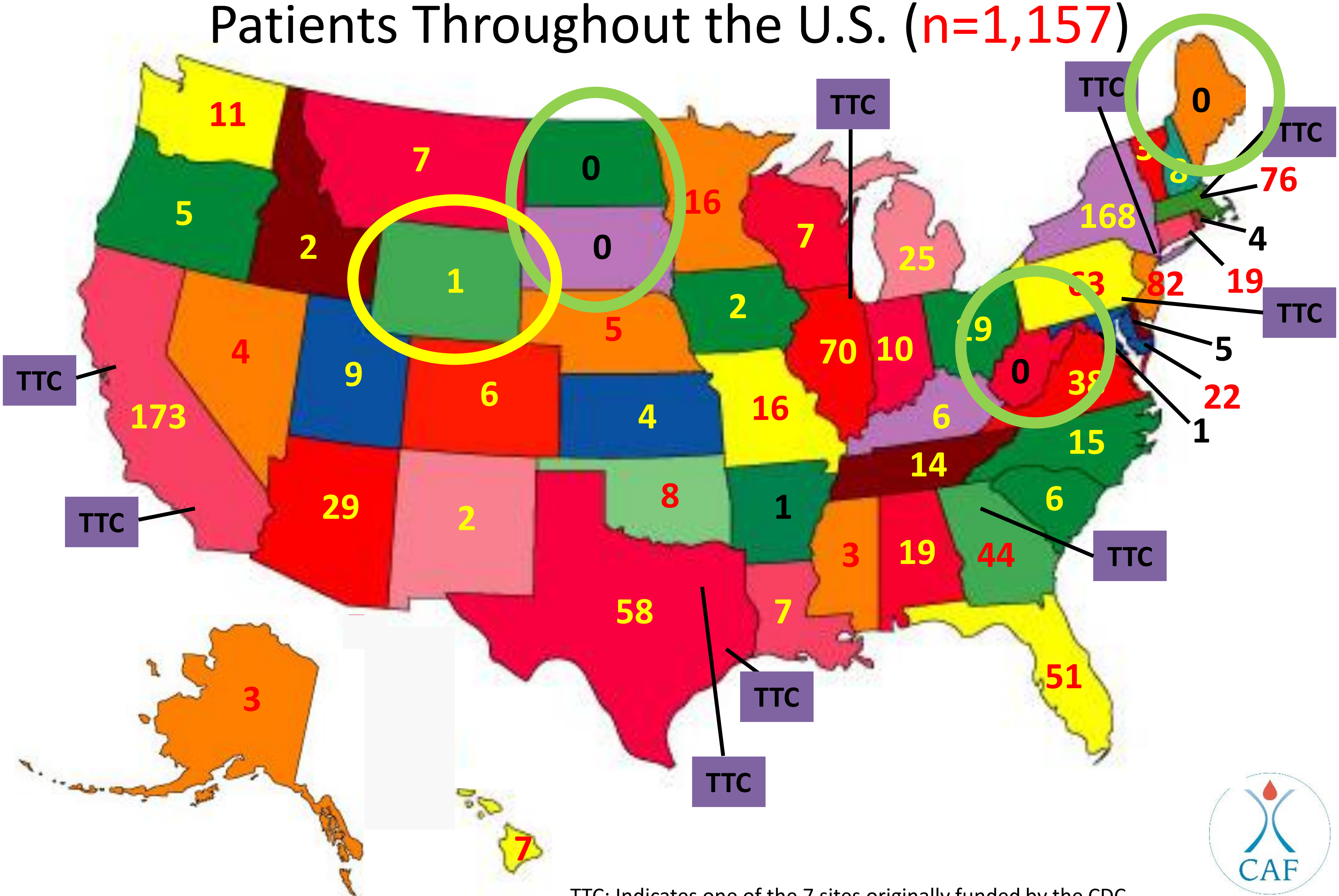

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Major Outreach Strategies that Enabled CAF to Discover 343 New U.S. Thalassemia Patients in 3.5 Years

(1) Partnering with TTCs to encourage new patient registration (105)

(2) Reaching out to network of adoptive families (55)

(3) New patients who registered with CAF online (37)

(4) New patients who signed up for Patient-Family Conferences (37)

(5) Registering patients who contact CAF for assistance (35)

Additional Outreach Strategies that Enabled CAF to Discover 343 New U.S. Thalassemia Patients in 3.5 Years

(6) Performing Site Visits/Town Halls to Thalassemia Centers (20)

(7) Reaching out via CAF's Facebook page (9)

(8) Conducting outreach to patients who appear in news media (4)

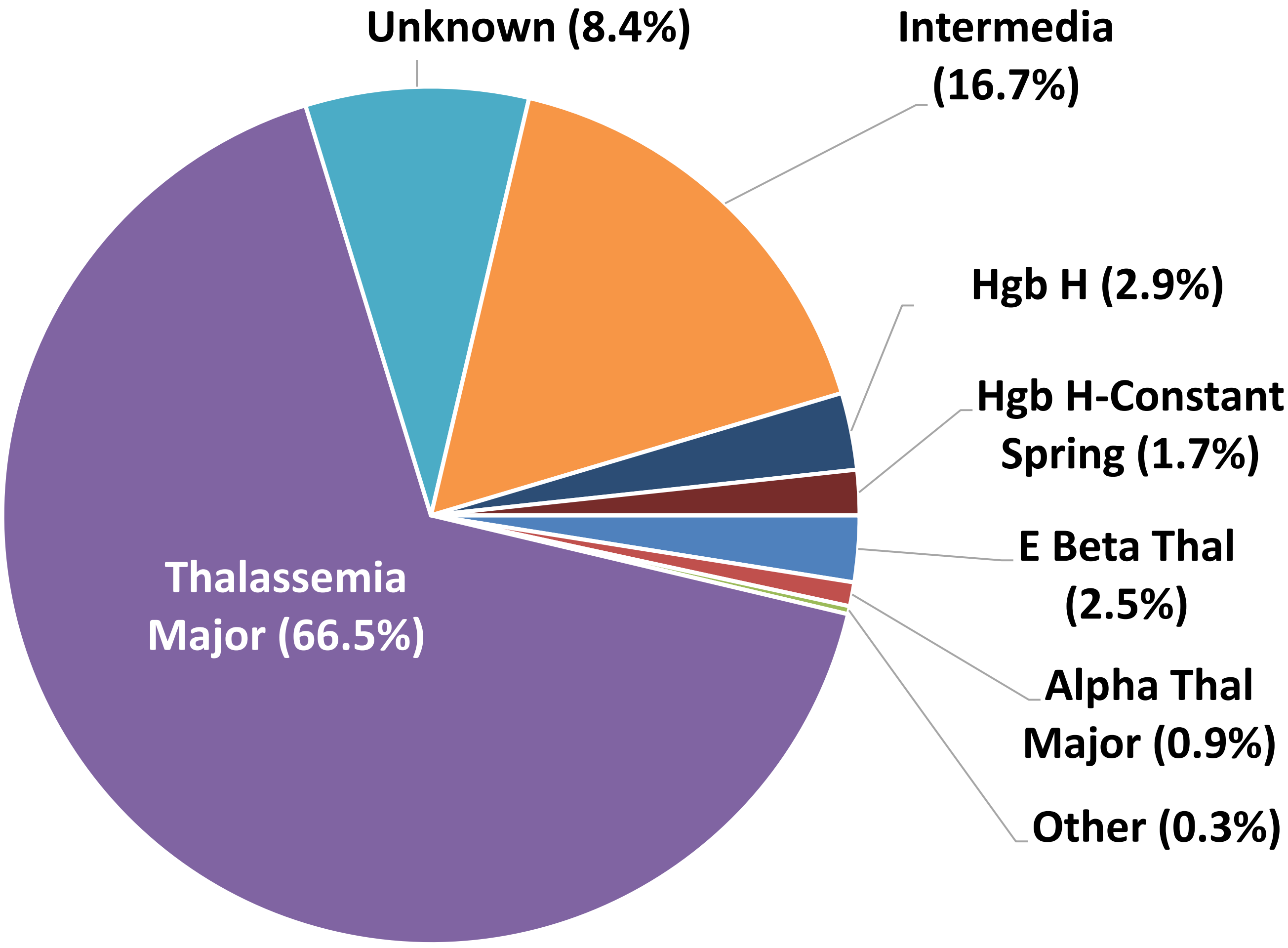
(9) Learned of new patients through CAF Chapter contacts (2)

(10) Other (39)

"Other" includes: (1) Learned of patients' siblings or cousins we were not already in contact with; (2) Posted patient survey on Facebook; (3) Reached out via other groups' Facebook pages; (4) New patients applied for Patient Incentive Awards; (5) Attended

Patient Database Provides Information on the Size and Demographics of the U.S. Thalassemia Patient Population

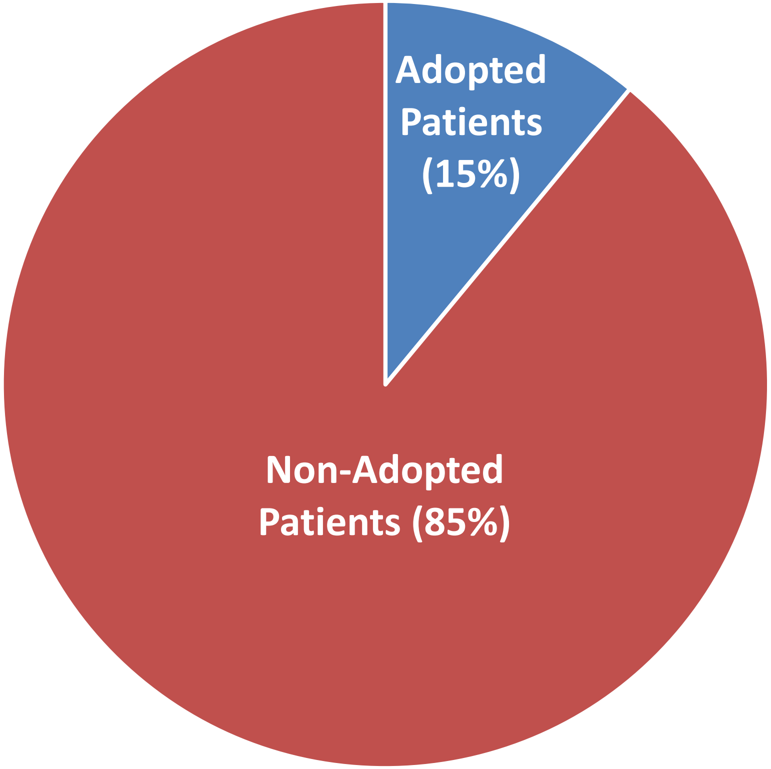
Diagnoses of Patients in CAF Patient Database (n=1,157)



NOTE: Diagnoses of "Other" includes Beta Thalassemia/Sideroblastic Anemia, and Autosomal Dominant Thalassemia

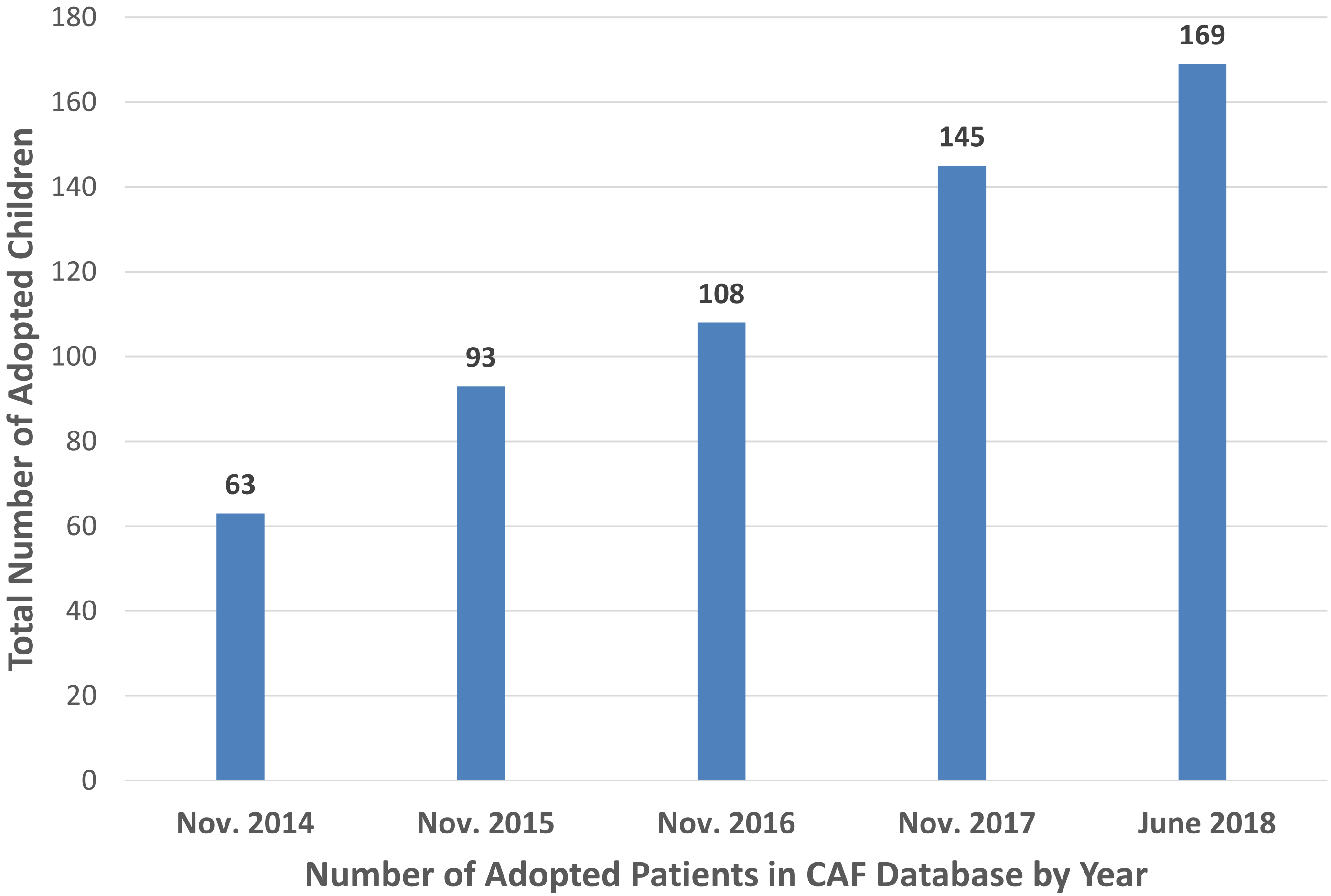
Adopted Thalassemia Patient Subset

International Adoption Currently Accounts for 15% of Patients in CAF Patient Database



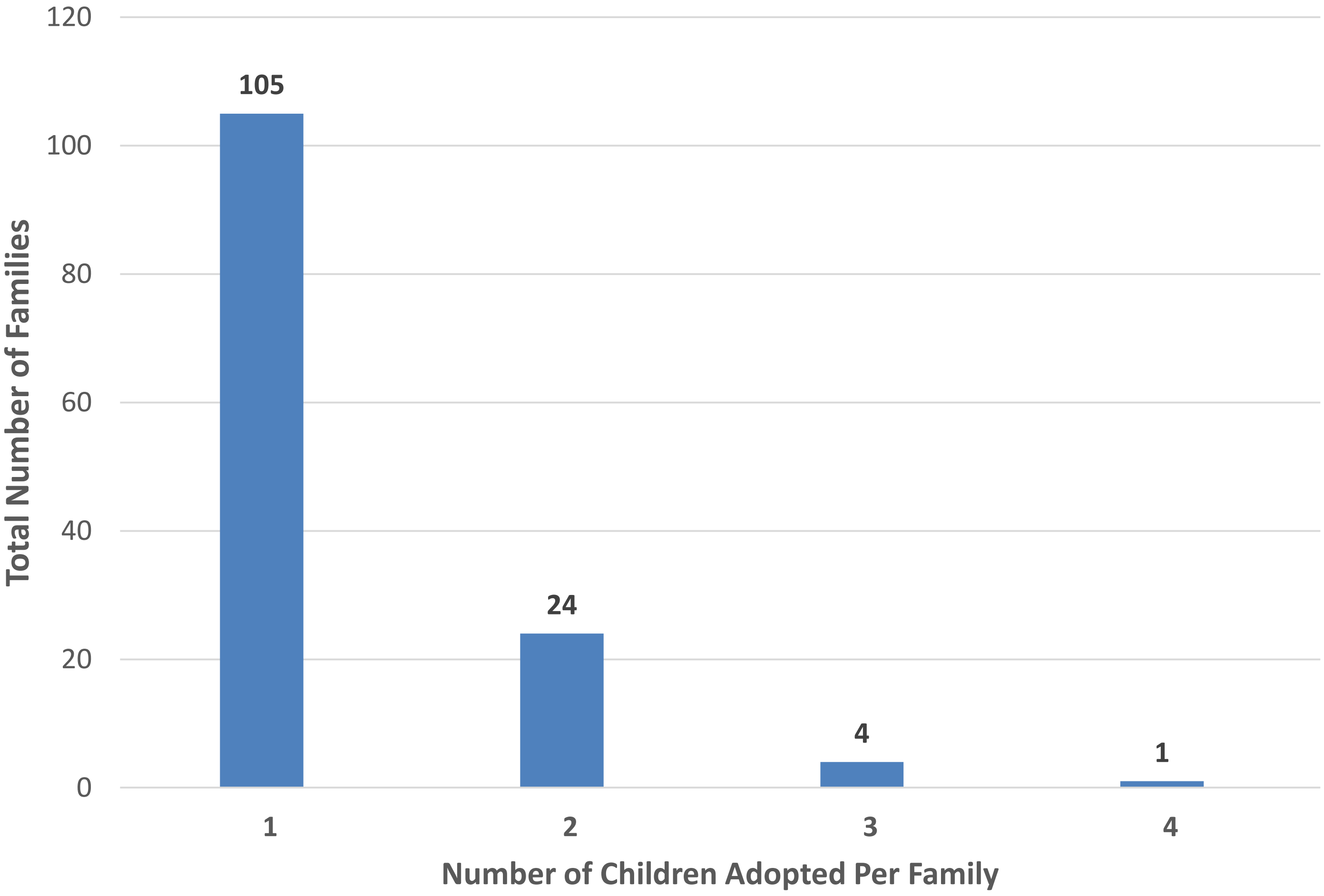
- **169/1157 (15%) of patients in the CAF Database have been adopted from other countries**

Adoption of Children with Thalassemia is a Growing Segment of Thalassemia Patient Population



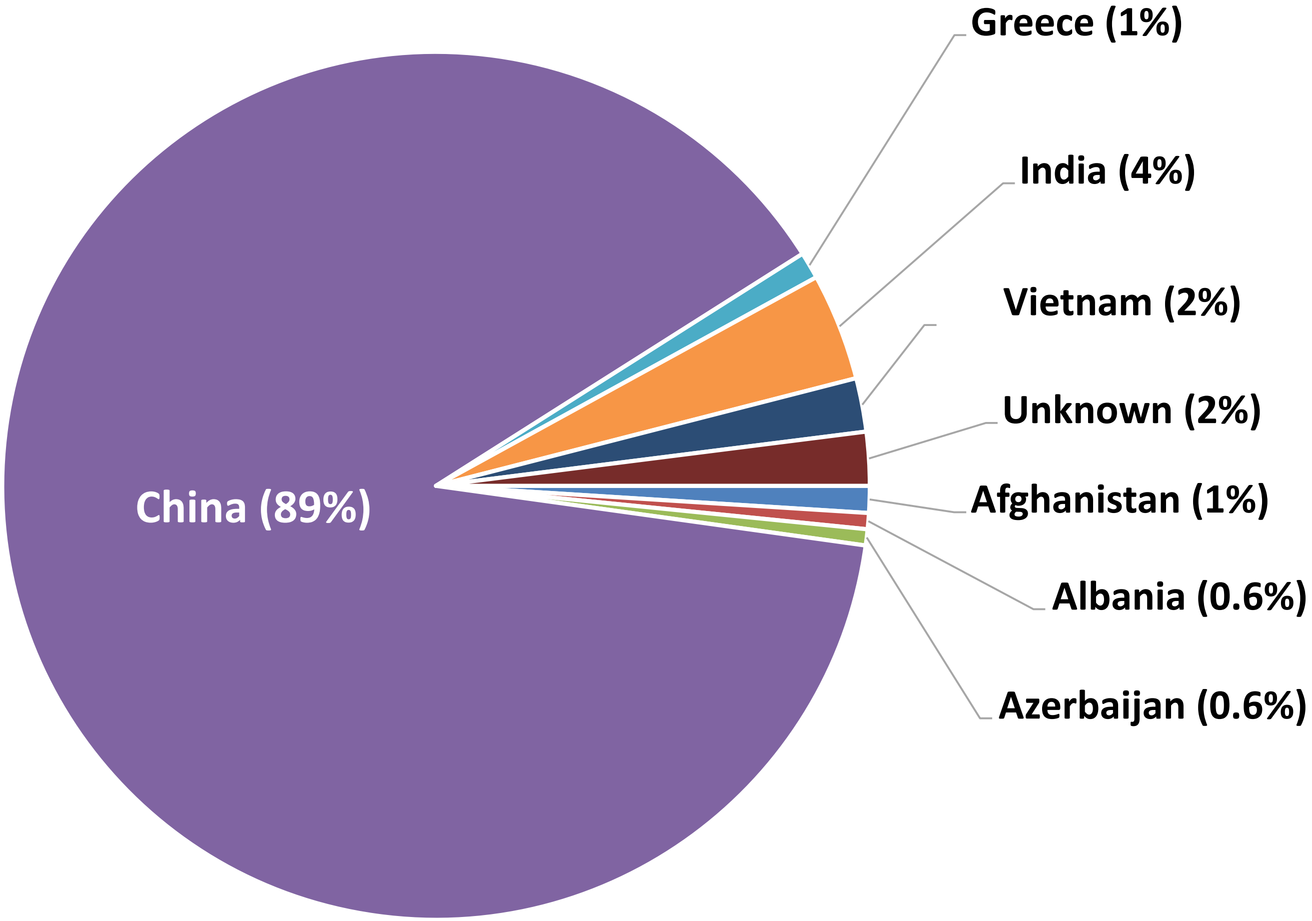
This represents a 2.7-fold increase in adoption of children with thalassemia since Nov. 2014

Some Families Have Adopted Multiple Children with Thalassemia



NOTE: 1 family with 2 adopted children adopted 1 child from China and 1 child from Albania.
The mother of one of the families that adopted 3 children has thalassemia herself.

Country-of-Origin of Adopted Thalassemia Patients in CAF Database (n=169)



- **89% of adopted thalassemia patients were born in China**
- **64% of adopted thalassemia patients are female**

Estimated Size of U.S. Thalassemia Patient Population

Current Geographical Distribution of Thalassemia Patients Throughout the U.S. (n=1,157)

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Almost 500 Thalassemia Patients Associated with Major TTCs are Not Present in CAF Database

Institution	Total # Patients	# Patients in CAF Dbase	# Patients Still Outstanding
(1) Children's Healthcare of Atlanta	88	68	20
(2) CHLA	~100	46	54
(3) Lurie Children's Hospital of Chicago	~150	79	71
(4) Hospital of University of Pennsylvania (adults)	40	23	17
(5) Children's Hospital of Philadelphia (pediatric)	160	75	85
(6) Children's Hospital Boston	125	92	33
(7) Weill Medical College of Cornell University	~150	93	57
(8) UCSF Benioff Children's Hospital Oakland	230	78	152
(9) Texas Children's Hospital, Houston	20	13	7
(10) Children's Medical Center, Dallas	19	17	2
TOTAL	1,082	584	**498**

~500 Thalassemia Patients Associated with 38 Sampled Treatment Centers Are Also Not Present in CAF Database

Institution	Total # Patients	# Patients in CAF Dbase	# Patients Still Outstanding
(1) Rady Children's Hospital	83	10	**73**
(2) Valley Children's Hospital	75	1	**74**
(3) Children's Hospital of Colorado	57	1	**56**
(4) Children's Hospitals & Clinics of Minnesota	64	11	**53**
(5) Phoenix Children's Hospital	30	16	**14**
(6) Children's Hospital of Orange County	20	3	**17**
(7) Kapiolani Medical Center	20	3	**17**
(8) Rutgers/Robert Wood Johnson Medical Group	20	4	**16**
(9) Seattle Children's Hospital	18	5	**13**
(10) Hackensack University Medical Ctr	15	5	**10**
(11) Other (28 additional centers)	177	43	**134**
TOTAL	579	102	**477**

Estimate of Total Number of Thalassemia Patients in United States

- CAF appears to be missing 975 patients associated with 48 sampled medical centers from its Database
- This brings the estimate of the total number of known thalassemia patients in the U.S. to 2,132
  - 1,157 known patients + 975 additional reported patients
  - This number would be higher if we continued to sample additional medical centers

Objective #2: Developing Public Health Messages for Thalassemia Community

CAF/CDC Public Health Messaging

- CAF/CDC have developed a bank of health messages over the years which are regularly disseminated on CAF social media and other channels
- Health messages are designed to be easily understood, memorable, and meaningful
- Whenever possible, health messages are evidence-based and supported by data
- New health messages are developed to address topics of greatest need/concern to the community

Health Messages Developed in Collaboration with CDC: Prevention of Complications

Testing for Low Bone Mass Helps Prevent Fractures.

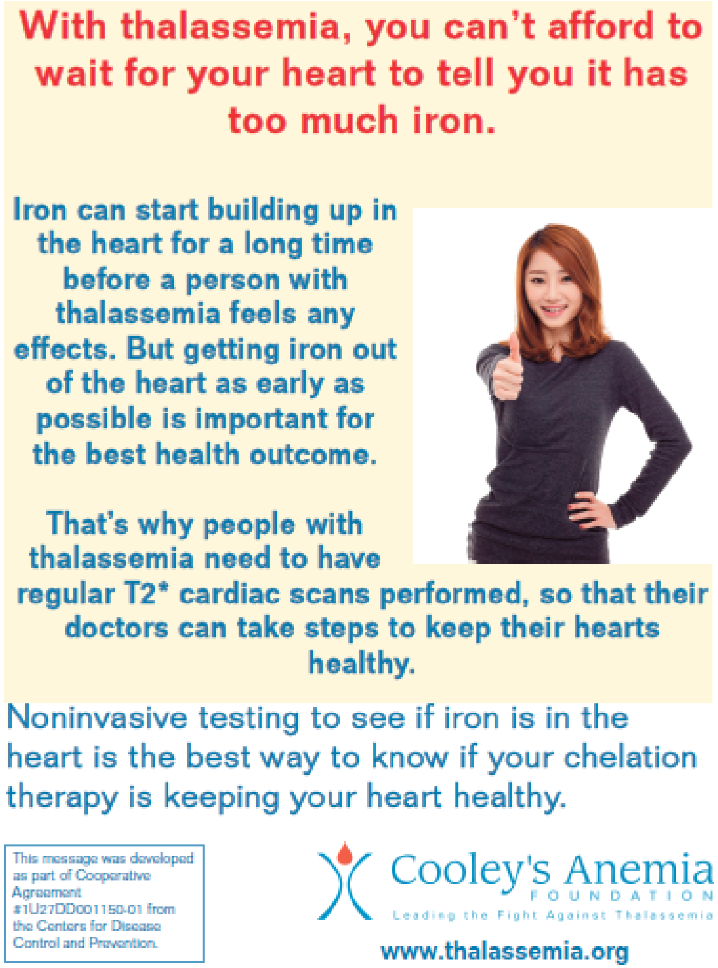
People with thalassemia have a greater risk of bone fracture due to low bone mass. Early identification of reduced bone mass may lead to strategies that can reduce the risk of fracture.

People with thalassemia should have a bone mass test (sometimes called a bone mineral density test) by age 10 and should repeat it annually or as needed. This applies to thalassemia patients whether they are transfused or non-transfused.

Early testing can help keep bones healthier and stronger. Talk with your doctor to learn more.

This message was developed as part of Cooperative Agreement #5NU27DD001150-04-00 from the Centers for Disease Control and Prevention.

Cooley's Anemia
FOUNDATION
Leading the Fight Against Thalassemia
www.thalassemia.org



With thalassemia, you can't afford to wait for your heart to tell you it has too much iron.

Iron can start building up in the heart for a long time before a person with thalassemia feels any effects. But getting iron out of the heart as early as possible is important for the best health outcome.

That's why people with thalassemia need to have regular T2* cardiac scans performed, so that their doctors can take steps to keep their hearts healthy.

Noninvasive testing to see if iron is in the heart is the best way to know if your chelation therapy is keeping your heart healthy.

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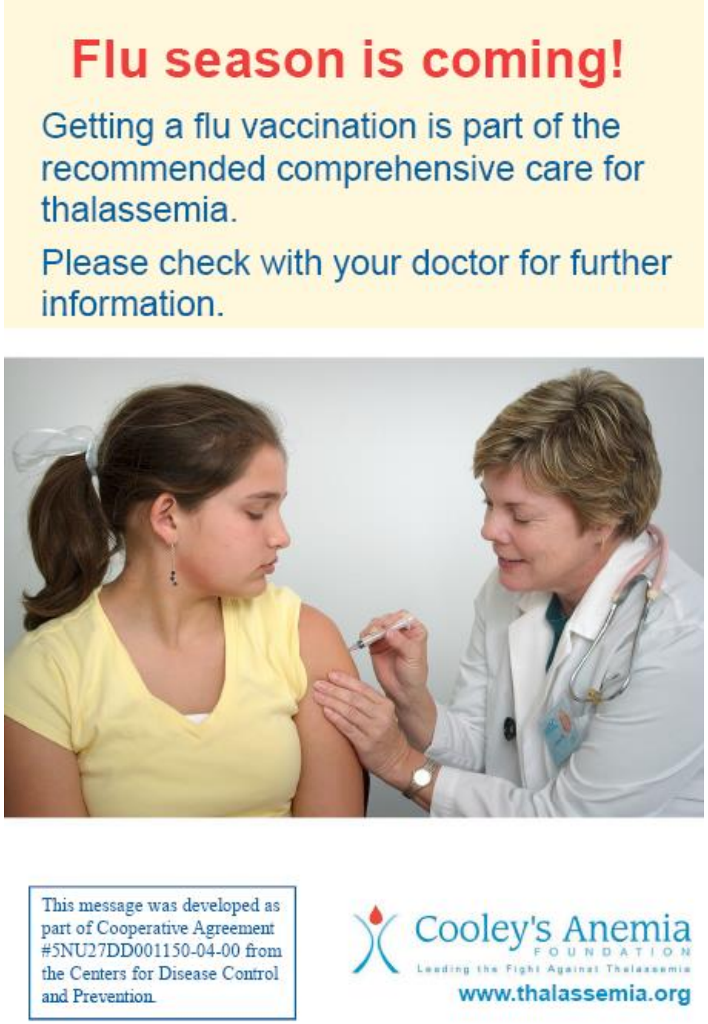
Health Messages Developed in Collaboration with CDC: Prevention of Illness



Flu season is coming!

Getting a flu vaccination is part of the recommended comprehensive care for thalassemia.

Please check with your doctor for further information.

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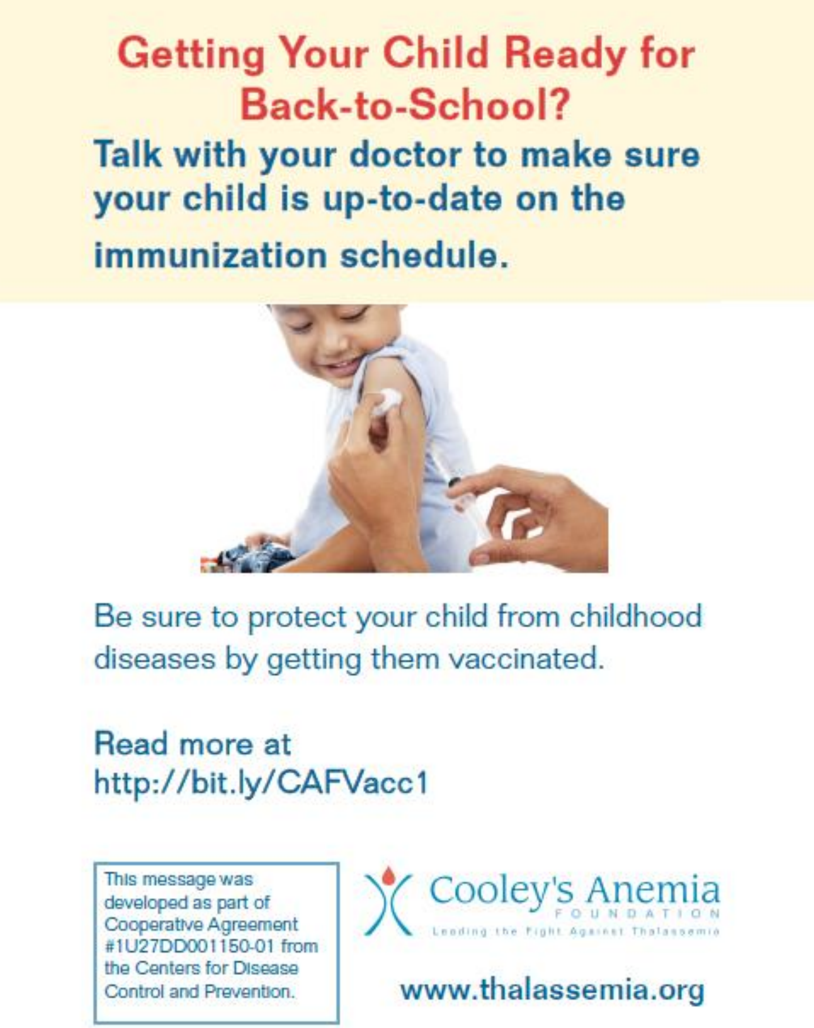

Getting Your Child Ready for Back-to-School?

Talk with your doctor to make sure your child is up-to-date on the immunization schedule.

Be sure to protect your child from childhood diseases by getting them vaccinated.

Read more at
http://bit.ly/CAFVacc1

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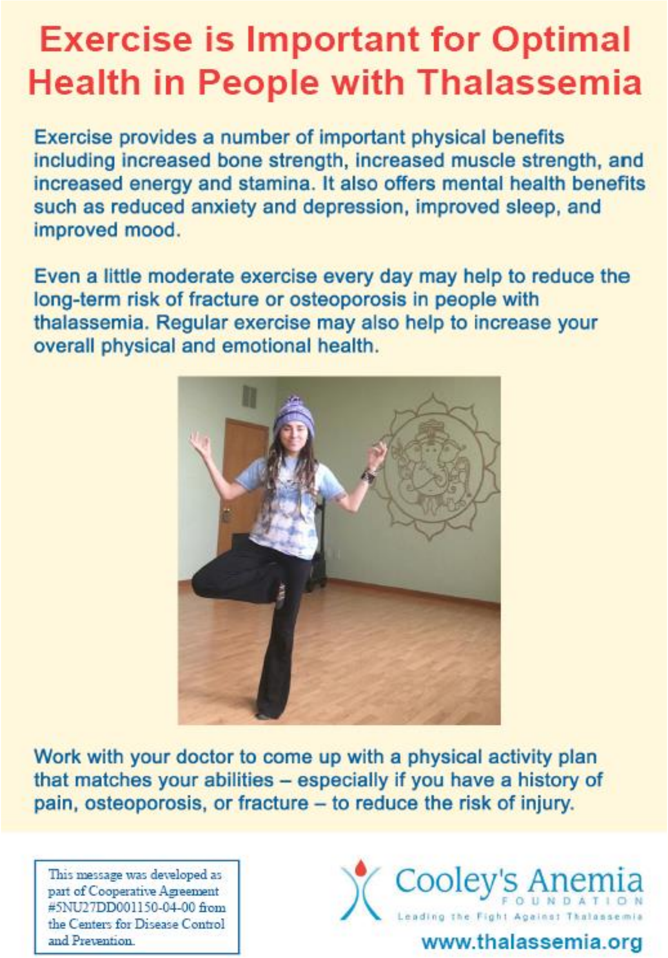
Health Messages Developed in Collaboration with CDC: Importance of Exercise in Thalassemia



Exercise is Important for Optimal Health in People with Thalassemia

Exercise provides a number of important physical benefits including increased bone strength, increased muscle strength, and increased energy and stamina. It also offers mental health benefits such as reduced anxiety and depression, improved sleep, and improved mood.

Even a little moderate exercise every day may help to reduce the long-term risk of fracture or osteoporosis in people with thalassemia. Regular exercise may also help to increase your overall physical and emotional health.

Work with your doctor to come up with a physical activity plan that matches your abilities – especially if you have a history of pain, osteoporosis, or fracture – to reduce the risk of injury.

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She has thalassemia – and still runs half marathons.

Joelle has thalassemia, but that doesn't prevent her from participating in endurance sports. She runs 10-20 miles every week and has completed multiple races, including half marathons.

As patients have gained **greater access to proper medical care** for thalassemia, their lifespan has increased and more are able to attend college, have a career, play sports and maintain long term relationships.

With good medical management, you can live a long, healthy, active life.

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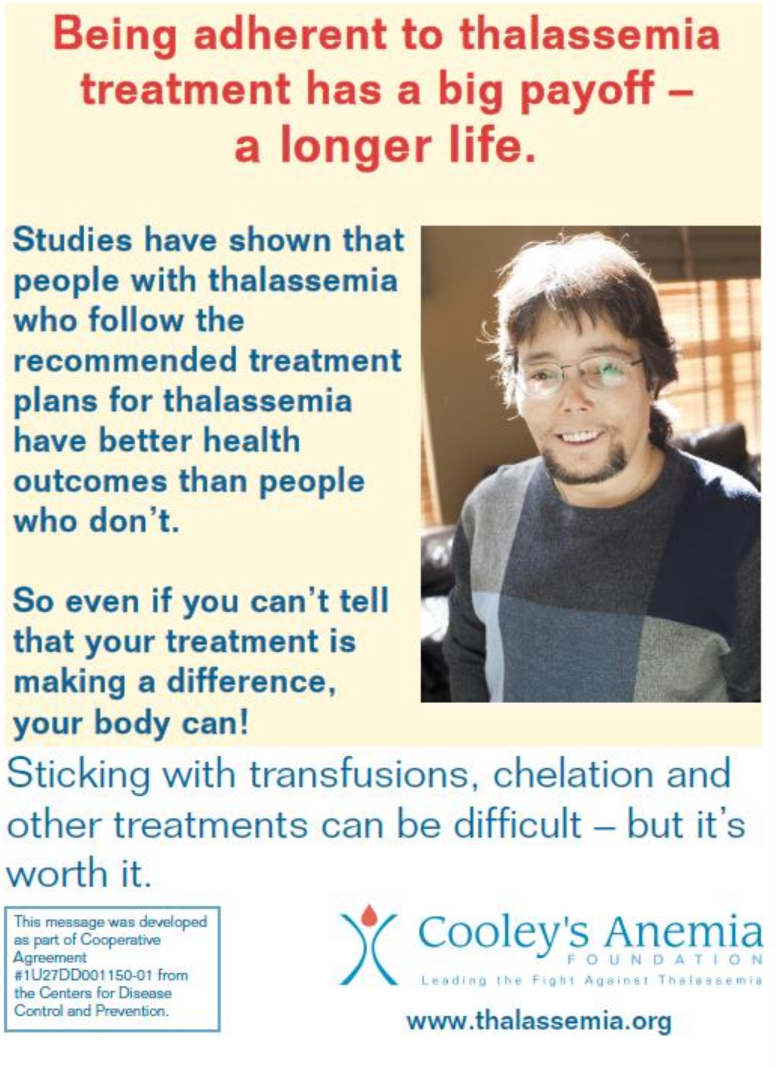
Health Messages Developed in Collaboration with CDC: Adherence to Chelation Therapy



Being adherent to thalassemia treatment has a big payoff – a longer life.

Studies have shown that people with thalassemia who follow the recommended treatment plans for thalassemia have better health outcomes than people who don't.

So even if you can't tell that your treatment is making a difference, your body can!

Sticking with transfusions, chelation and other treatments can be difficult – but it's worth it.

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CAF

Health Messaging Will be Focused by Topic in the Year Ahead

- CAF/CDC will conduct a themed health messaging campaign throughout 2018-2019
  - This will disseminate targeted and credible information on several themes on social media
  - The messaging will address disease management strategies throughout the lifespan

(1) Focus on Pediatric Patients (*Oct. 2018 - Dec. 2018*)

(2) Focus on Adult Patients (*Jan. 2019 - March 2019*)

(3) Adherence and Thalassemia Management (*April 2019 - June 2019*)

(4) Thalassemia-Related Complications (*July 2019 - Sept. 2019*)

Videos: Navigating the Transition to Adult Care

- The transition from pediatric to adult care is an area of great concern for many patients
- CAF/CDC are developing short videos of 2 patients describing their experiences with transition to adult care
  - CDC TV studio has already filmed the interview with Robert Mannino

Robert Mannino, PhD

Aaron Cheng, MD candidate

Objective #3: Increase Awareness of Thalassemia Trait and the Importance of Trait Testing

The American College of Obstetricians and Gynecologists (ACOG) Guidance on Thalassemia Trait Screening

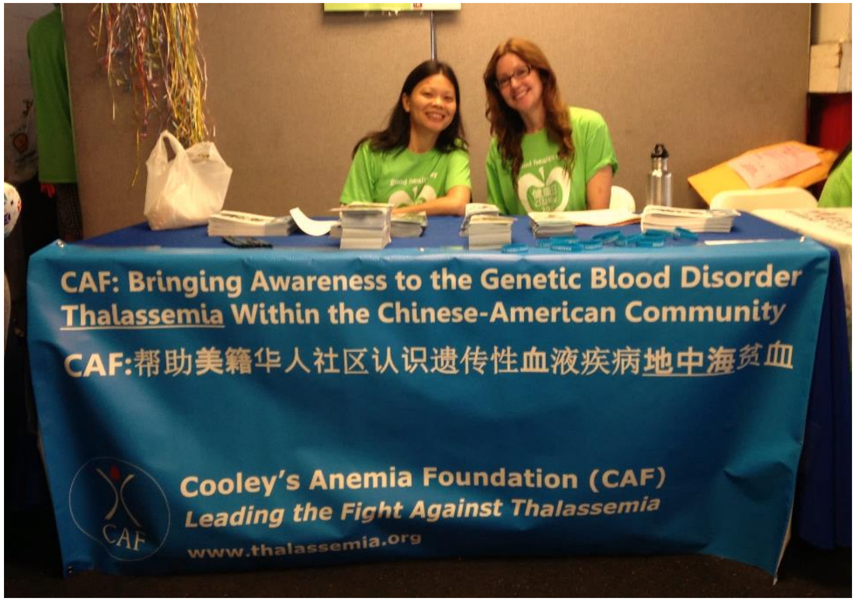
- At the 2017 CAF Patient-Family Conference, Cindy Sayers of the CDC gave a presentation on “Thalassemia as a Public Health Issue”
- Afterwards, a parent approached Cindy/CAF stating that neither he nor his wife had any knowledge of their carrier status until their child was born and diagnosed with thalassemia
  - He asked if there was anything we could do to improve physicians’ awareness of the need to perform thalassemia trait testing during family planning
- ACOG has published detailed guidance on thalassemia trait screening
  - CAF drafted a summary of ACOG’s guidance on Thalassemia Trait Screening, which is posted on CDC’s Thalassemia website

The American College of Obstetricians and Gynecologists (ACOG) Guidance on Thalassemia Trait Screening (cont'd)

- Prevention of thalassemia through carrier screening is important to ACOG. They educate physicians about the need for trait screening as follows:
  - CME program: Genomics 101: What is Genomics Counseling, and Why is it Important?
  - CME e-module on Genetics
  - ACOG sends out daily membership updates to their membership which occasionally highlights genetics education topics
  - ACOG annual meeting offers courses on genetics and carrier screening
- ACOG is considering whether there may be other opportunities to collaborate with CAF to spread awareness about the need for trait screening

CAF Tries to Increase Awareness of Thalassemia in At-Risk Communities

- CAF participates in an annual Health Fair in NYC’s Chinatown
- Brochures about trait testing are distributed in both Chinese and English
- Booth is staffed by thalassemia patients/families who speak both Mandarin and Cantonese
- 2,000 visitors attend this event each year
- Many of our booth visitors were already aware of the high prevalence of thalassemia in the Chinese community
  - Some had even been tested for thalassemia trait



Conclusions

- CAF has added 343 thalassemia patients to its Patient Database since Nov 2014
- The CAF Database currently includes 1,157 patients
- There are approximately 975 patients from 48 medical centers who are currently missing from the CAF Database
- The total number of U.S. thalassemia patients may therefore be 2,132 and could be even higher
- CAF will continue to develop health messages/educational materials to support the needs of the U.S. thalassemia population