ARIZONA HOUSE OF REPRESENTATIVES
Fifty-second Legislature – Second Regular Session

MINUTES RECEIVED
CHIEF CLERK'S OFFICE
1-13-16

COMMITTEE ON HEALTH

Report of Regular Meeting
Tuesday, January 12, 2016
House Hearing Room 4 -- 2:00 p.m.

Convened 2:19 p.m.
Recessed
Reconvened
Adjourned 3:22 p.m.

Members Present
Mr. Boyer
Mr. Friese
Mr. Lawrence
Mr. Meyer
Mrs. Cobb, Vice-Chairman
Mrs. Carter, Chairman

Members Absent

Agenda
Original Agenda – Attachment 1

Request to Speak
None

Presentations

Name	**Organization**	**Attachments** (Handouts)
Katie Sosnowski	Postural Orthostatic Tachycardia Syndrome (P.O.T.S)	2
Charis Ober	Save the Cord Foundation	3

Committee Action

Bill	**Action**	**Vote**	**Attachments** (Summaries, Amendments, Attendance)
	Committee Attendance		4

Sandy Kelley, Chairman Assistant
January 13, 2016

(Original attachments on file in the Office of the Chief Clerk; video archives available at http://www.azleg.gov)

Convened: 2:19 pm
adjourned: 3:22 pm

ARIZONA HOUSE OF REPRESENTATIVES
Fifty-second Legislature - Second Regular Session

REGULAR MEETING AGENDA

COMMITTEE ON HEALTH

DATE Tuesday, January 12, 2016 ROOM HHR 4 TIME 2:00 P.M.

Members:

Mr. Boyer	Mr. Lawrence	Mrs. Cobb, Vice-Chairman
Mr. Friese	Mr. Meyer	Mrs. Carter, Chairman

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1. Introduction of Committee Members and Staff
2. Presentations
   - Katie Sosnowski, Postural Orthostatic Tachycardia Syndrome (P.O.T.S.)
   - Charis Ober, Executive Director and Founder, Save the Cord Foundation

Heather Carter, Chairman

slk
1/7/16

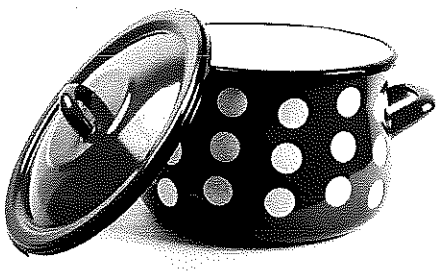
People with disabilities may request reasonable accommodations such as interpreters, alternative formats, or assistance with physical accessibility. If you require accommodations, please contact the Chief Clerk's Office at (602) 926-3032, TDD (602) 926-3241.

Attachment 1

POTS:
Postural Orthostatic Tachycardia Syndrome

Katie Sosnowski
Undergraduate, University of Arizona

What POTS is NOT:



Attachment 1

"So what *is* POTS?"

- Postural Orthostatic Tachycardia Syndrome
- Term was created in 1993 by Mayo Clinic researchers[4]
- A form of dysautonomia
  - means the autonomic nervous system is not functioning properly[4]
- When a patient stands up:
  - Dizziness
  - Weakness
  - Fast heart rate (tachycardia)
  - Shortness of breath[9]
- Chronic symptoms include: fatigue, insomnia, light/noise sensitivity, migraines, brain fog, heat intolerance, nausea, vomiting, diarrhea, constipation, weight loss/gain[5,9]
- Symptoms are "invisible," unpredictable, and place a daunting financial and emotional toll on family[5]

My Life with POTS

- About a year of symptoms before receiving my diagnosis in November 2012
- Fatigue, weakness, breathing problems, pain, stomach problems, swallowing difficulty, etc. with no explainable cause
- Switched to online school in 10th grade, often couldn't attend church, etc.
- Finally diagnosed at the Mayo Clinic in Minnesota
- Began following rigorous treatment plan, follow-up appointments with Mayo Clinic in AZ
- Now: I have graduated from high school and am attending the University of Arizona to study biomedical engineering

So what is the problem?

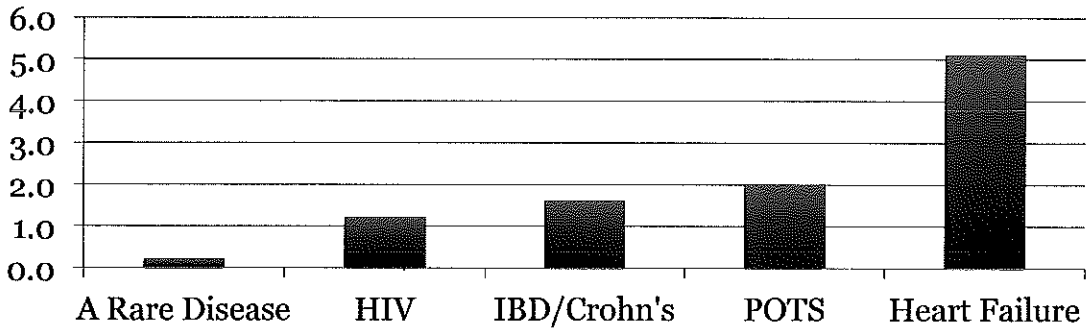
- I was fortunate to finally receive a diagnosis in less than a year
- Average time spent finding diagnosis is **5 years, 11 months**[4]
- Misdiagnoses of depression/anxiety are common[6]
- It's not just citizens...most doctors haven't heard of POTS either
- No cure to date – only able to treat symptoms
- Major lack of research on the condition and its proper treatment

I would love to see Arizona be a state that recognizes and supports POTS patients so they do not suffer for such a long time!

It's Not Rare

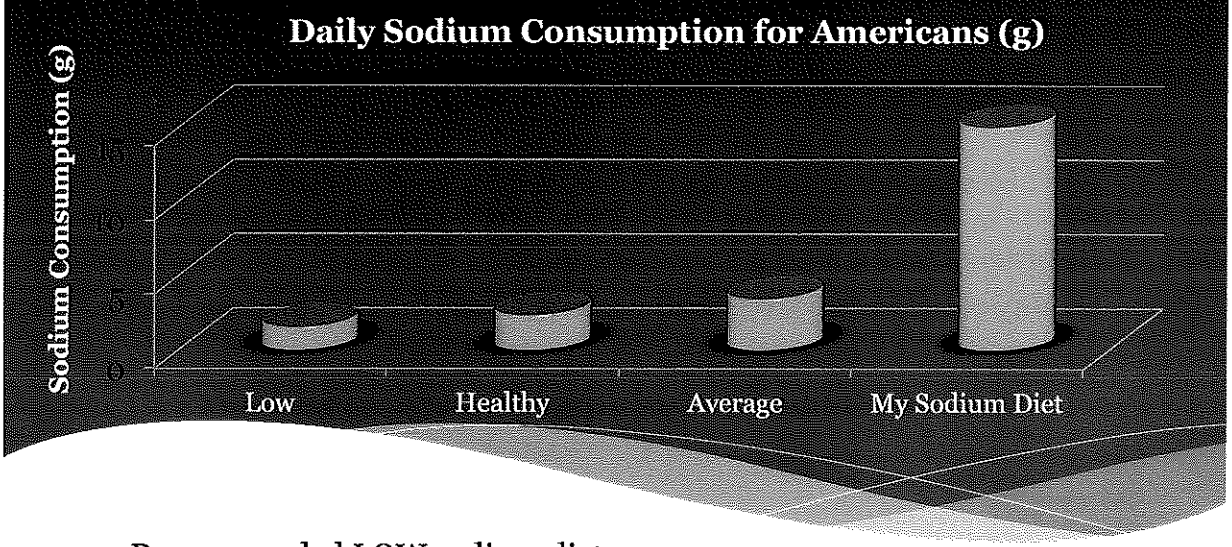
- POTS may affect 1 in 100 teens in the US and 1 to 3 million Americans total[4]
- Can't be considered rare – a rare disease affects fewer than 200,000 people in the US according to the National Organization for Rare Disorders (NORD)[8]
- Quality of life is compared to illnesses such as COPD, congestive heart failure, and patients on dialysis for kidney failure[4]

Prevalence of Illnesses in US (in millions of people)[1,2,3,4,8]



Treatment of POTS

"So you just add a little salt to your diet?"

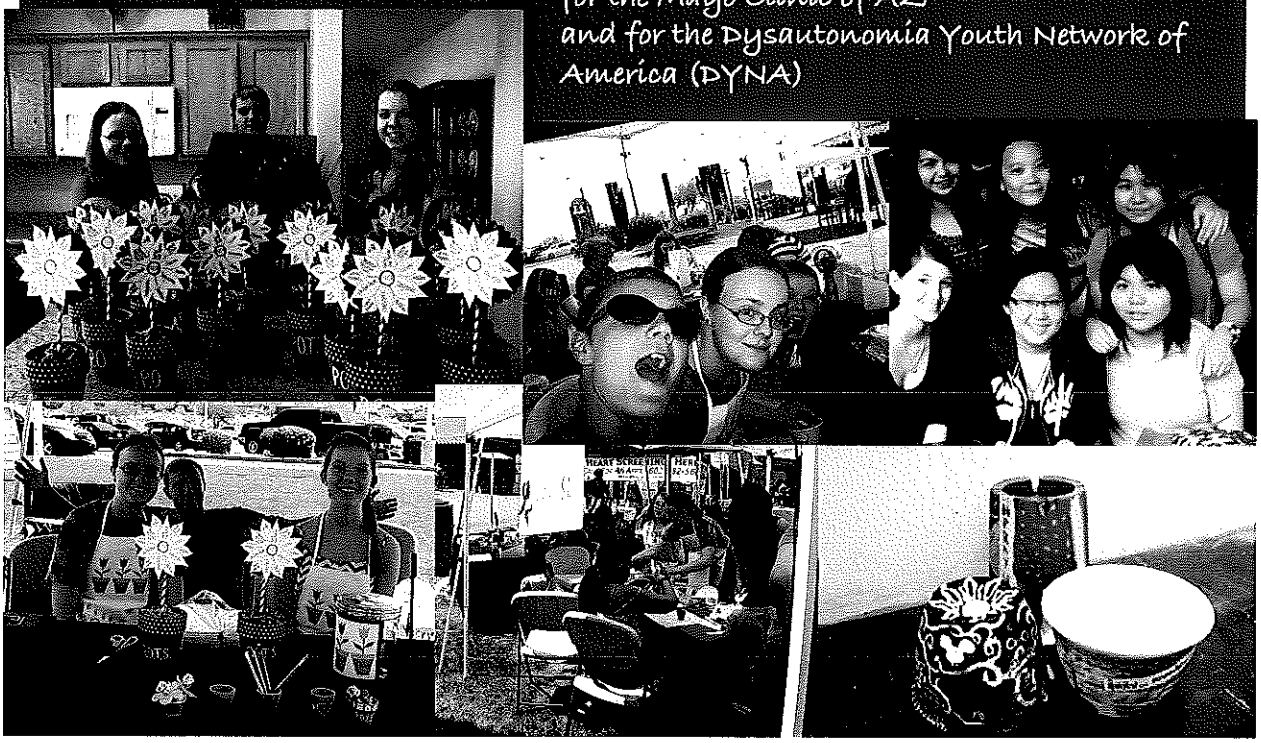


- Recommended LOW sodium diet = <1.5g
- Recommended NORMAL sodium diet = <2.3g
- AVERAGE American's sodium diet = 3.4g (scandalous!)
- Recommended sodium diet for POTS patients = **10 to 20g** (!!!)

(See References 6, 7)

Raising Awareness and Research Money

for the Mayo Clinic of AZ
and for the Dysautonomia Youth Network of America (DYNA)



References

1. Centers for Disease Control and Prevention (2015, September 29). HIV in the United States: At a glance. Retrieved from http://www.cdc.gov/hiv/statistics/overview/ataglance.html

2. Centers for Disease Control and Prevention (2015, November 30). Heart failure fact sheet. Retrieved from http://www.cdc.gov/dhdsp/data_statistics/fact_sheets/fs_heart_failure.htm

3. Crohn's and Colitis Foundation of America (2014, November). Fact book highlights. Retrieved from http://www.ccfa.org/assets/pdfs/updatedibdfactbook.pdf

4. Dysautonomia International (2012). What is dysautonomia?, Postural orthostatic tachycardia syndrome, and 10 facts doctors should know about POTS. Retrieved from http://www.dysautonomiainternational.org/page.php?ID=34 ,http://www.dysautonomiainternational.org/page.php?ID=30, and http://www.dysautonomiainternational.org/page.php?ID=180

5. Dysautonomia Youth Network of America (2002-2015). Symptoms/Impact. Retrieved from http://www.dynainc.org/dysautonomia/symptoms

6. Goodman, B.P. (2007). Approach to the evaluation of small fiber peripheral neuropathy and disorders of orthostatic intolerance. *Seminars in Neurology, 27*(4), 347-355.

7. Mayo Clinic Staff (2013, May 30). Sodium: How to tame your salt habit. Retrieved from http://www.mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/sodium/art-20045479

8. National Organization for Rare Disorders (2015). Resources & FAQs. Retrieved from https://rarediseases.org/for-patients-and-families/information-resources/resources-faqs/

9. Sandroni, P., Opfer-Gehrking, T.L., McPhee, B.R., and Low, P.A. (1999). Postural tachycardia syndrome: Clinical features and follow-up study. *Mayo Clinic Proceedings, 74*, 1106-1110.

Arizona PUBLIC CORD BLOOD PROGRAM

Cord Blood Presentation to the AZ House Health Committee

Charis Ober

Save the Cord Foundation

January 12, 2016

Arizona Department of Health Services

Arizona Biomedical Research Commission

Grants • Biospecimen Locator • Education • Public Cord Blood

Abrazo Central Campus

Dignity Health St. Joseph's Hospital and Medical Center

Tucson Medical Center

MIHS Maricopa Integrated Health System

Maricopa County Special Health Care District

save the cord foundation

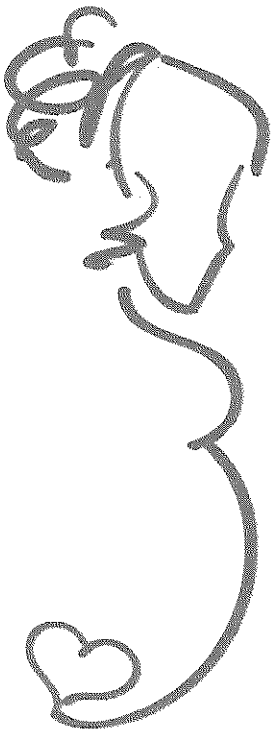
CLINIMMUNE LABS

Attachment 3

Arizona PUBLIC CORD BLOOD PROGRAM

Objectives

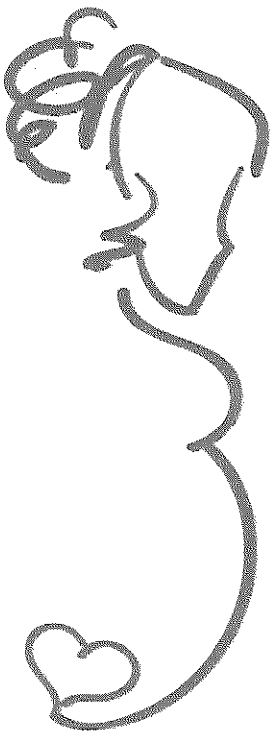
- Explanation of umbilical cord blood as a resource vs medical waste
- History of AZ cord blood program
- When is cord blood collected?
- How is cord blood collected?
- Why cord blood?
- Why collect in Arizona?
- Benefits to Arizona



Arizona PUBLIC CORD BLOOD PROGRAM

What is Umbilical Cord Blood?

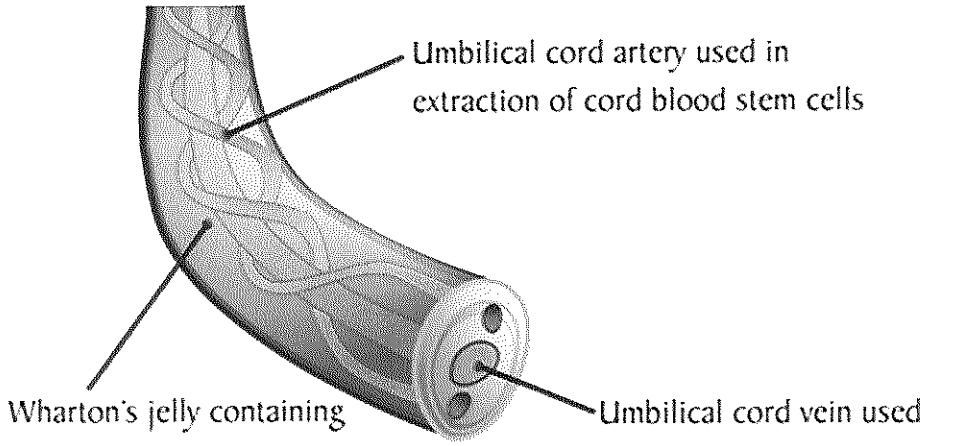
- Blood left in the umbilical cord **after a baby is born**
- Collection **does not harm** the baby or the mother
- A unique source of **life-saving stem cells**
- Historically, has been seen as **medical waste**
- Today, is **collected and stored** around the world, both privately and publicly

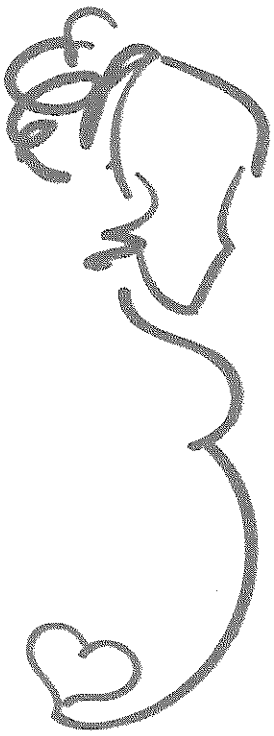


Arizona PUBLIC CORD BLOOD PROGRAM

What is Umbilical Cord Blood?

- Technically, umbilical cord blood is
  - White and red blood cells, platelets and plasma rich in **blood forming stem cells**
  - **Used much like bone marrow** to regenerate a weakened or sick immune system





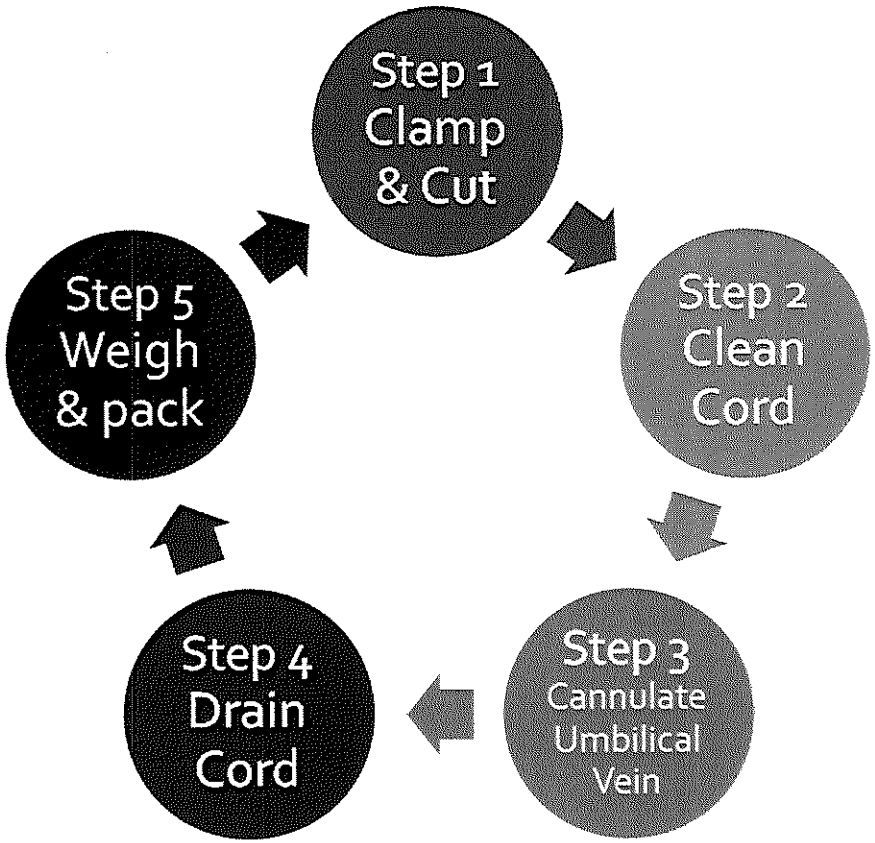
Arizona PUBLIC CORD BLOOD PROGRAM

When to Collect

- After obtaining patient's written consent
- Between birth and delivery of placenta
- OB provider collects into bag
- Cryopreserved (frozen) within 48 hours

Arizona PUBLIC CORD BLOOD PROGRAM

How Umbilical Cord Blood is Collected

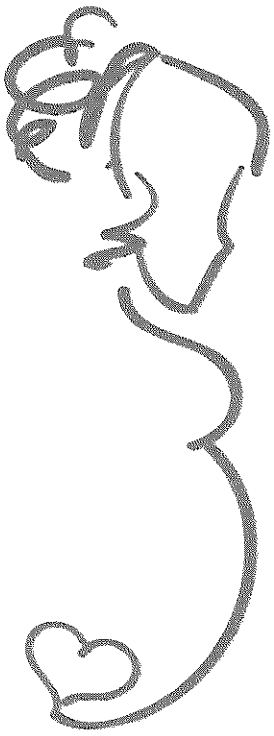


- Baby is not touched
- The mom and baby are not harmed

Arizona PUBLIC CORD BLOOD PROGRAM

Why Cord Blood is Donated

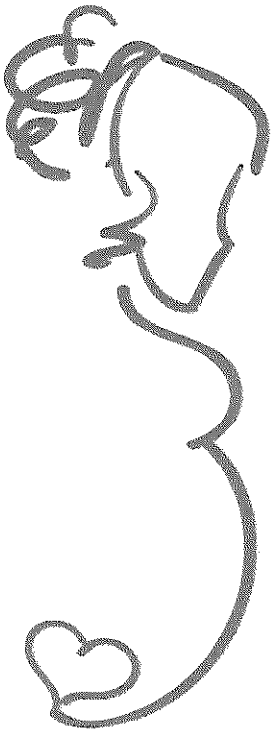
- Donation is free
- 80 diseases currently treated or cured
- **30** life-saving cord blood units transplanted from Arizona's donations!
- Over 5,000 units banked and registered with the National Cord Blood Inventory
- Cord blood is often the best or only hope for a cure for many patients with one of many life-threatening diseases
- Non-transplantable cord blood units may be made available for research



Arizona PUBLIC CORD BLOOD PROGRAM

Diseases Treated with Cord Blood

- Malignancies: leukemia, lymphoma
- Blood Disorders: Sickle cell anemia, Thalassemia Aplastic anemia, and Fanconi anemia
- Immunodeficiencies: Severe combined immunodeficiency syndrome (SCID), Kostmann syndrome
- Metabolic Disorders: Hurler syndrome, Krabbe disease, Sanfilippo syndrome
- Future: Regenerative medicine

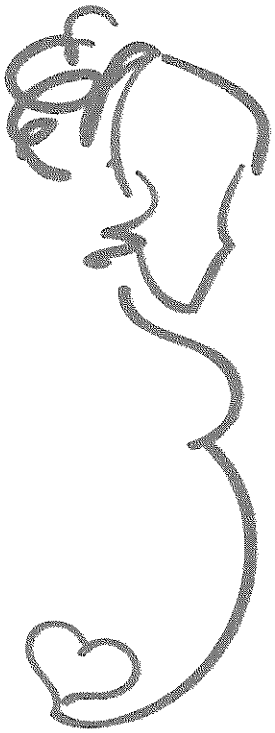


Arizona PUBLIC CORD BLOOD PROGRAM

Recipient Stories

Noah Swanson receiving umbilical cord blood transplant to treat myelodysplastic syndrome

https://youtu.be/0x-cLe88Ijk

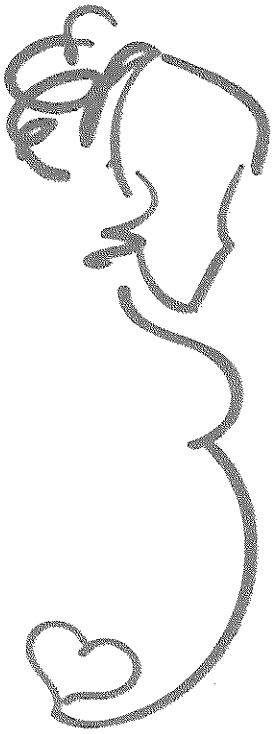


Arizona PUBLIC CORD BLOOD PROGRAM

Recipient Stories

Michelle and Erik Praskins explain how the decision of a complete stranger saved their son Dylan's life.

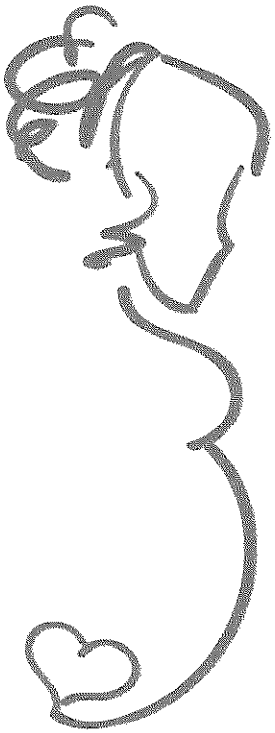
http://azdhs.gov/biomedical/#az-public-cord-blood-program



Arizona PUBLIC CORD BLOOD PROGRAM

History

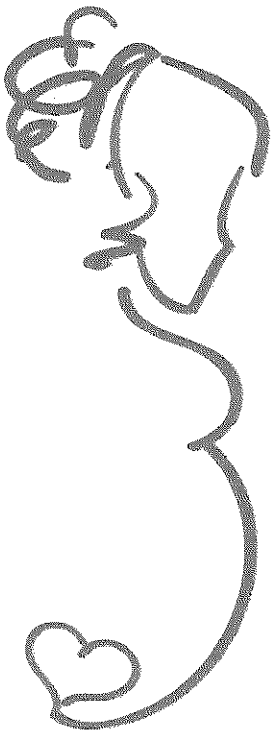
- Arizona is a leader in the field of public cord blood collection
  - Statute § 32-3212
    - January 1, 2007
    - OB providers are required to provide information to expectant parents about saving cord blood
  - Arizona Public Cord Blood Program Established in 2011



Arizona PUBLIC CORD BLOOD PROGRAM

Why Collect in Arizona

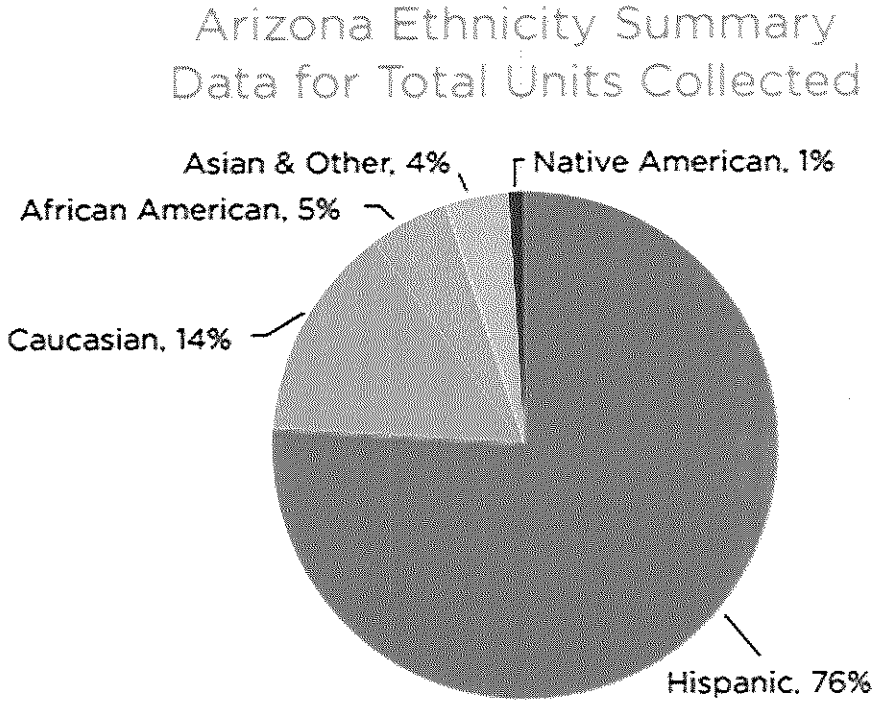
- Ethnic diversity
- Unique gene pool
- Facts about minority transplants
  - — Adding diverse units to registry increases the likelihood of a match
  - — 7 out of 10 people don't have a suitably matched donor in the family and depend on the National Marrow Donor Program
  - — In 2014, 29% of cord blood transplants worldwide were for minority patients.



Arizona PUBLIC CORD BLOOD PROGRAM

Arizona Public Cord Blood Program

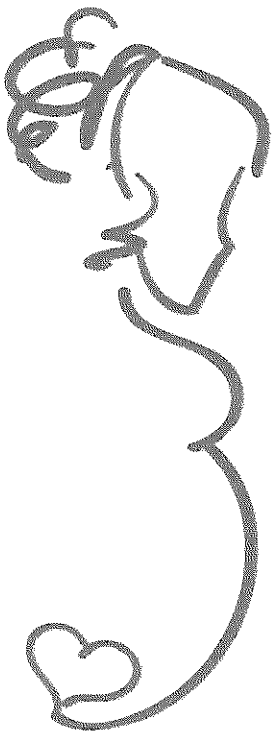
The Arizona Public Cord Blood Program was created to advance the collection of and increase the number of ethnically diverse cord blood units available for transplantation.



Arizona PUBLIC CORD BLOOD PROGRAM

Benefits to our State

- Advocating for and addressing the needs of underserved and diverse citizens of our state
- Providing education and outreach
- Resource for AZ researchers
- Attracting cellular, biological and technology businesses and organizations
- Cellular platform for our state

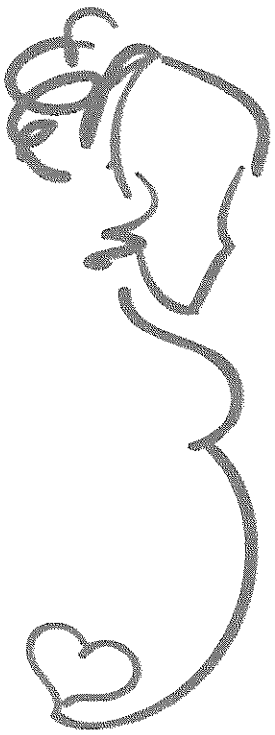


The 6th C of Arizona
Cattle
Cotton
Climate
Copper
Citrus
It's Cells... Stem cells are the medicine of the future
and a good business and education platform
for our state!

Arizona PUBLIC CORD BLOOD PROGRAM

Education Outreach

- Expectant parents
- Health professionals
- The public
- The next generation



Arizona PUBLIC CORD BLOOD PROGRAM

Current Collaborating Partners

Arizona Department of Health Services
Arizona Biomedical Research Commission
Grants • Biospecimen Locator • Education • Public Cord Blood

Abrazo Central Campus

Dignity Health. St. Joseph's Hospital and Medical Center

Tucson Medical Center

MIHS
MARICOPA INTEGRATED HEALTH SYSTEM
Maricopa County Special Health Care District

save the cord foundation

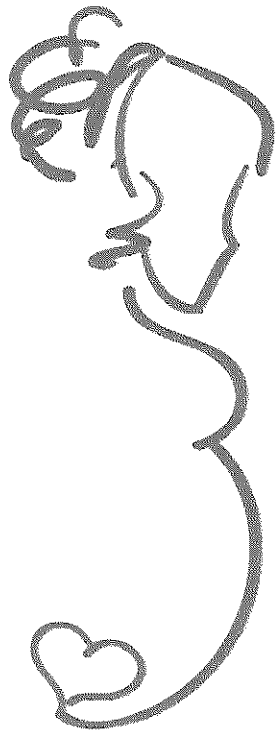
CLINIMMUNE LABS

Arizona PUBLIC CORD BLOOD PROGRAM

Arizona Biomedical Research Commission

- 4 distinct programs:
  - Research Grant
  - Arizona Public Cord Blood Program
  - Arizona Biospecimen Locator
  - Research Education

- Multiple initiatives guided by input from leaders and professionals from Arizona's
  - universities
  - nonprofit research institutions
  - hospitals
  - medical centers
  - patient advocacy groups



Arizona
PUBLIC
CORD BLOOD PROGRAM

- Arizona Biomedical Research Commission

Victor Waddell, Executive Director • Jennifer Botsford, Program Manager • Theresa Napoleon, Program Coordinator

(602)364-0157 • CordBloodInfo@azdhs.gov

www.azdhs.gov/biomedical/#az-public-cord-blood-program

- Charis Ober, Save the Cord Foundation

charis.ober@savethecordfoundation.org

www.savethecordfoundation.org

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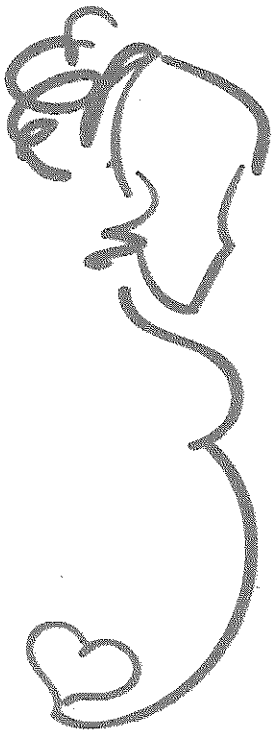
Arizona PUBLIC CORD BLOOD PROGRAM

Questions?

Thank you!



ARIZONA STATE LEGISLATURE

Fifty-second Legislature - Second Regular Session

COMMITTEE ATTENDANCE RECORD

COMMITTEE ON **HEALTH**

CHAIRMAN: Heather Carter VICE-CHAIRMAN: Regina Cobb

	DATE	1/12/16	/16	/16	/16	/16
	CONVENED	2:19pm	m	m	m	m
	RECESSED					
	RECONVENED					
	ADJOURNED	3:22pm				
MEMBERS						
Mr. Boyer		✓				
Mr. Friese		✓				
Mr. Lawrence		✓				
Mr. Meyer		✓				
Mrs. Cobb, Vice-Chairman		✓				
Mrs. Carter, Chairman		✓				

√ Present --- Absent exc Excused

Attachment 4