

EMS Integration with Special Medical Needs

A look into the success of collaboration, legislation, education and solutions created and adopted in Missouri

Presented By:

Darlene Shelton, President
Danny's Dose Alliance

Dr. Brian Froelke, MD, FACEP
Assistant Professor Washington
University, Saint Louis

Patricia Casey, EMT-P
STARS Program Coordinator

2011

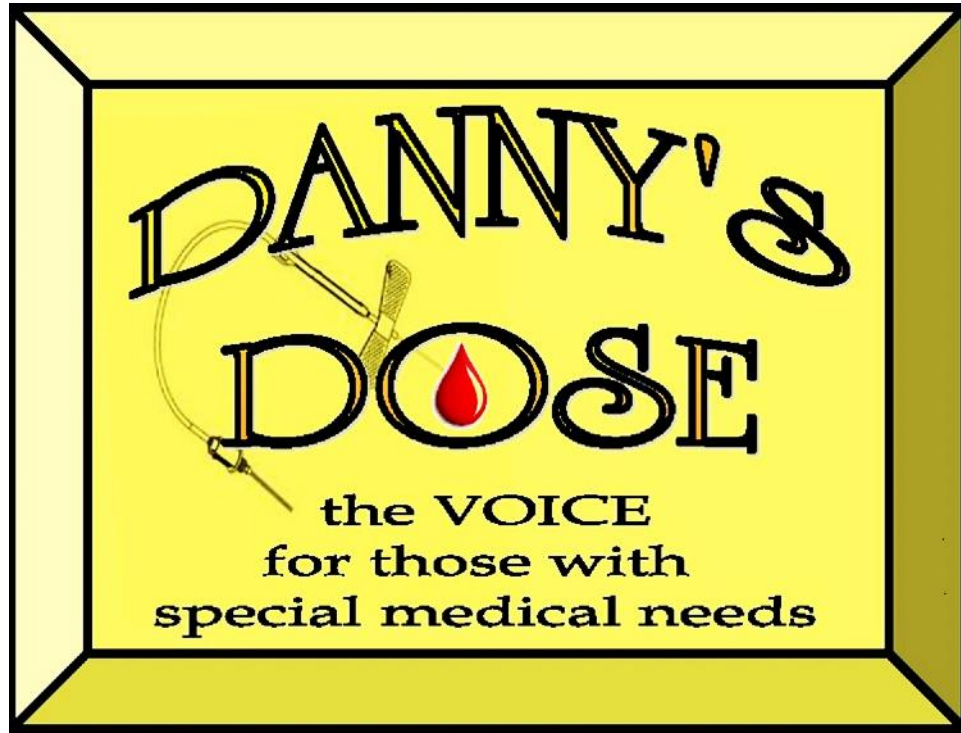
2 weeks before we became a
“special medical needs” family



3 1/2 years later...

We realized children across the U.S are not
protected and became part of the solution





3 Main Goals:

- ☐ Raise awareness to the gap in emergency treatment protocols for special needs patients & see changes made
- ☐ Work with and help create specialized education for emergency personnel
- ☐ Educate families on their role in their protection



Collaborate

Listen

Relationships

Awareness

Educate

Safety

Care Plans

Teams

Protect

Work

How prevalent is the issue?

- 13 conditions requiring life-saving emergency medications
= over 23 Million Americans
- 17 more requiring specialized life-saving treatments
= **over 26 Million Americans**

{These #s are based on our current research data and continually increasing}



What can be done?

Missouri and Minnesota are the first 2 states to pass EMS legislation and are great examples of

- ❖ Collaboration
- ❖ Legislation
- ❖ Protections
- ❖ New Regulations
- ❖ Education
- ❖ Implementation
- ❖ **SUCCESSSES**

Missouri EMS -- Setting the Scene

- The Basics:
 - Missouri is broken into hundreds of local municipalities and districts with an equally large number of local EMS Agencies
 - Missouri recognizes local Medical Control and individualized medical director protocols rather than state-wide protocols
 - RSMO 190-142 “4. All levels of emergency medical technicians may perform only that patient care which is:
 - Consistent with the training, education and experience of the particular emergency medical technician; and
 - Ordered by a physician or set forth in protocols approved by the medical director.
 - Missouri has a State Advisory Council on EMS made up of stakeholders and experts to advise the Governor, Legislation and the Department of Health on EMS related topics
 - Missouri is broken into 6 EMS regions based upon patient flow each with its own EMS subcommittee
 - Missouri has a Time Critical Diagnosis System which recognizes Stroke, STEMI and Trauma and coordinates appropriate patient destinations for patients with those conditions.

Darlene's Case Example

- Did you know that some patients are dying because EMS are not allowed to give them their life saving medications?
- EMS and some Emergency providers don't know what to do for patients with rare diseases and special medical needs.
- We are changing the law to fix this problem!



Initial Response

EMS already knows about life threats

Just Contact Online
Medical Control

Our protocols are State of the
Art and Evidence Based

Physicians should
practice medicine not
legislators

Short Transport Times
make this irrelevant for
our agency

Ambulance space limited
we have no room for
more meds

We don't need another law!

ED can deal with it when EMS gets there

We won't mess with any meds other than our own formulary



Further Evaluation

- When we walked through the case with the State Advisory Committee and discussions with statewide experts we identified several gaps in the existing system.
- We recognized an opportunity to work with patient advocates, stakeholders, EMS experts, medical organizations, and legislature to derive a unique solution.
- Let's build this correctly so we don't have to keep making changes and we address everyone's needs



EMS Advisory Council is Key to Success

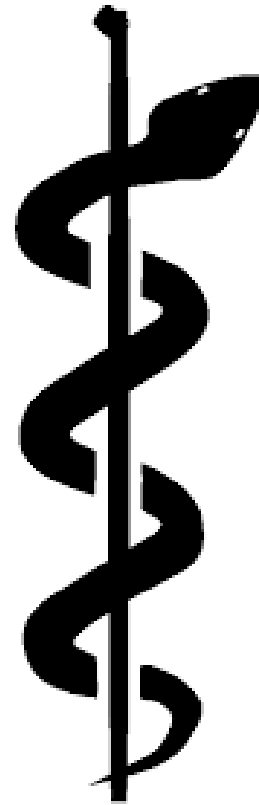
- Our EMS Advisory Council proved to be the key to Success
 - Trusted collaboration of EMS experts and key stakeholders working together
 - Central point of contact to coordinate efforts across all parties
 - Invitation to patient advocates to speak about patient centered impressions and concerns and needs
 - Subcommittees to help with specialty areas such as pediatrics and legislative/regulation development
 - Attended by members of several statewide and national organizations—NAEMSP, NREMT, ACEP, MOCEP, NASEMSO, ENA, MAA, MOEMS, EMS-C and many others.

The Goal

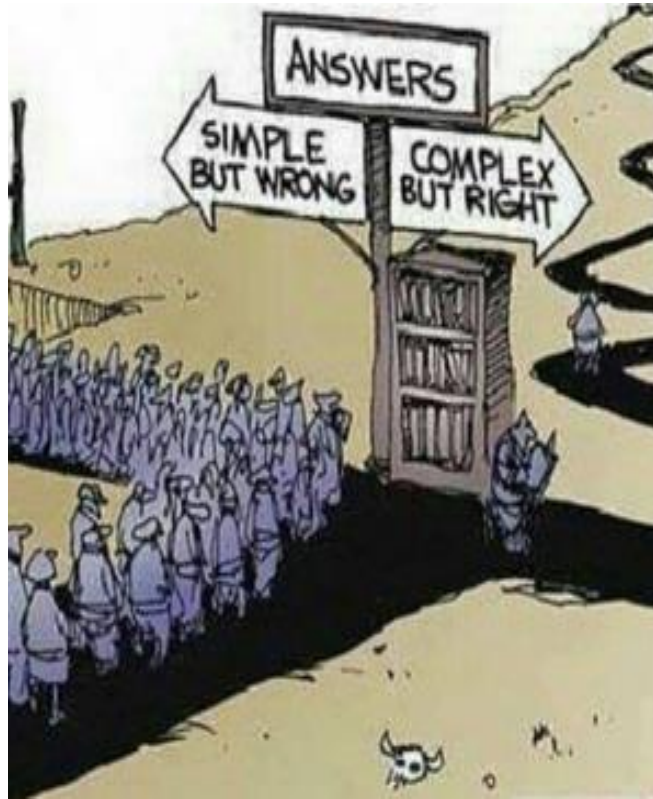
Pass a Law to create a Framework that Empowers and Protects Physician Experts to build an Evidence Based System based upon the Medical Model.



VS.



Our Solution



- **190.103. Regional EMS medical director, powers, duties — considered public official, when — online telecommunication medical direction permitted — treatment protocols for special needs patients. —** 1. One physician with expertise in emergency medical services from each of the EMS regions shall be elected by that region's EMS medical directors to serve as a regional EMS medical director. The regional EMS medical directors shall constitute the state EMS medical director's advisory committee and shall advise the department and their region's ambulance services on matters relating to medical control and medical direction in accordance with sections [190.001 to 190.245](#) and rules adopted by the department pursuant to sections [190.001 to 190.245](#). The regional EMS medical director shall serve a term of four years. The southwest, northwest, and Kansas City regional EMS medical directors shall be elected to an initial two-year term. The central, east central, and southeast regional EMS medical directors shall be elected to an initial four-year term. All subsequent terms following the initial terms shall be four years. The state EMS medical director shall be the chair of the state EMS medical director's advisory committee, and shall be elected by the members of the regional EMS medical director's advisory committee, shall serve a term of four years, and shall seek to coordinate EMS services between the EMS regions, promote educational efforts for agency medical directors, represent Missouri EMS nationally in the role of the state EMS medical director, and seek to incorporate the EMS system into the health care system serving Missouri.
- 5. Regional EMS medical directors and the state EMS medical director elected as provided under subsection 1 of this section shall be considered public officials for purposes of sovereign immunity, official immunity, and the Missouri public duty doctrine defenses.

Our Solution *(continued)*

- 6. The state EMS medical director's advisory committee shall be considered a peer review committee under section [537.035](#).
- 8. When developing treatment protocols for special needs patients, regional EMS medical directors may promulgate such protocols on a regional basis across multiple political subdivisions' jurisdictional boundaries, and such protocols may be used by multiple agencies including, but not limited to, ambulance services, emergency response agencies, and public health departments. Treatment protocols shall include steps to ensure the receiving hospital is informed of the pending arrival of the special needs patient, the condition of the patient, and the treatment instituted.
- 9. Multiple EMS agencies including, but not limited to, ambulance services, emergency response agencies, and public health departments shall take necessary steps to follow the regional EMS protocols established as provided under subsection 8 of this section in cases of mass casualty or state-declared disaster incidents.
- 10. When regional EMS medical directors develop and implement treatment protocols for patients or provide online medical direction for patients, such activity shall not be construed as having usurped local medical direction authority in any manner.
- 11. Notwithstanding any other provision of law to the contrary, when regional EMS medical directors are providing either online telecommunication medical direction to AEMTs, EMT-Bs, EMT-Ps, and community paramedics, or offline medical direction per standardized EMS treatment, triage, and transport protocols for patients, those medical directions or treatment protocols may include the administration of the patient's own prescription medications.

State EMS Medical Directors

- Establishes the State EMS Medical Director in Statute.
 - Previous versions were grant funded or subject to elimination during budget cuts, role was not clearly defined
 - Makes this an elected position, accountable to the regional EMS Medical Directors and the local physicians that they serve.
 - Provides an essential EMS physician leader to coordinate between statewide and national initiatives and ensures stable representation for our state

Regional Medical Directors and Legal Protections

- Recognizes that the EMS Medical Directors Committee in coordination with the State Advisory Council on EMS has the proper expertise to manage and coordinate this complex EMS medical system with the State EMS Medical Director as the lead
 - May establish/recognize subcommittees/programs to further meet the needs of these responsibilities
- Formally recognizes Regional and State EMS Medical Directors as public officials for purposes of medical legal protections
 - This also offers some protections for those working under those protocols
 - Frees local medical directors to adopt/reference regional guidelines
- Ensures physician leadership of this medical care and offsets many physician group's concerns about a law by providing limited protections
 - Essential for administration of patient own medications due to perceived risks associated with giving medications out of complete control of the agency
 - Essential for development of collaborative efforts due to variations in levels of legal protections between the different types of medical responders

The Medical Model and Local Control

- Enables the Regional Medical Directors to coordinate cross agency and cross geographical protocols
 - Allows interface with hospitals, urgent cares and other medical resources
 - Provides an empowered expert group to engage with advocates, patients and the communities to address current and future needs and areas of growth for EMS
 - Ensures that the medical providers can adopt changes to protocols, guidelines and systems at the speed of medical evidence
 - Ensures that medical evidence is applied to any associated legal changes to dissuade special interest or other political processes from pushing through unwelcomed or poorly designed medical rules
- Ensures that the Regional Medical Directors do not usurp local medical control
 - No one is losing any control nor power
 - This is enabling legislation for coordination and collaboration
 - Dislike it? Vote out the elected physicians and/or opt out of a troublesome regional protocol
- Establishes a peer review committee to protect Quality Improvement activities
 - Protects providers engaging in case reviews and patient safety event analysis to ensure data analysis protection, recognition of unanticipated consequences, and the increased power to recognize more rare events

Implementation Regional Medical Directors Approving Programs

- Programs applying for official authorization must meet the following criteria:
 - Designated Medical Director
 - Quality Improvement Program
 - Standardized, EMS friendly, care plans
 - Plans updated minimally annually and preferentially maintain living online documentation
 - Non-discriminatory
 - Integration with other emergency services
 - Maintains appropriate patient care protections including consents, HIPPA compliance and other digital and PHI related requirements
 - Education and training
 - Reports to the Region's EMS Medical Directors and consults with Special Medical Needs Advisory Committee

Special Needs Tracking and Awareness Response System

Tricia Casey, EMT-P, Dr. Steven Laffey, MD





Our Complex Kids are at Risk.

- **Pediatric patients with complex medical needs are the fastest growing subset of patients in the United States.**

** At Cardinal Glennon Children's Hospital we showed a 41% increase in tracheostomies performed from 2017-2018.*

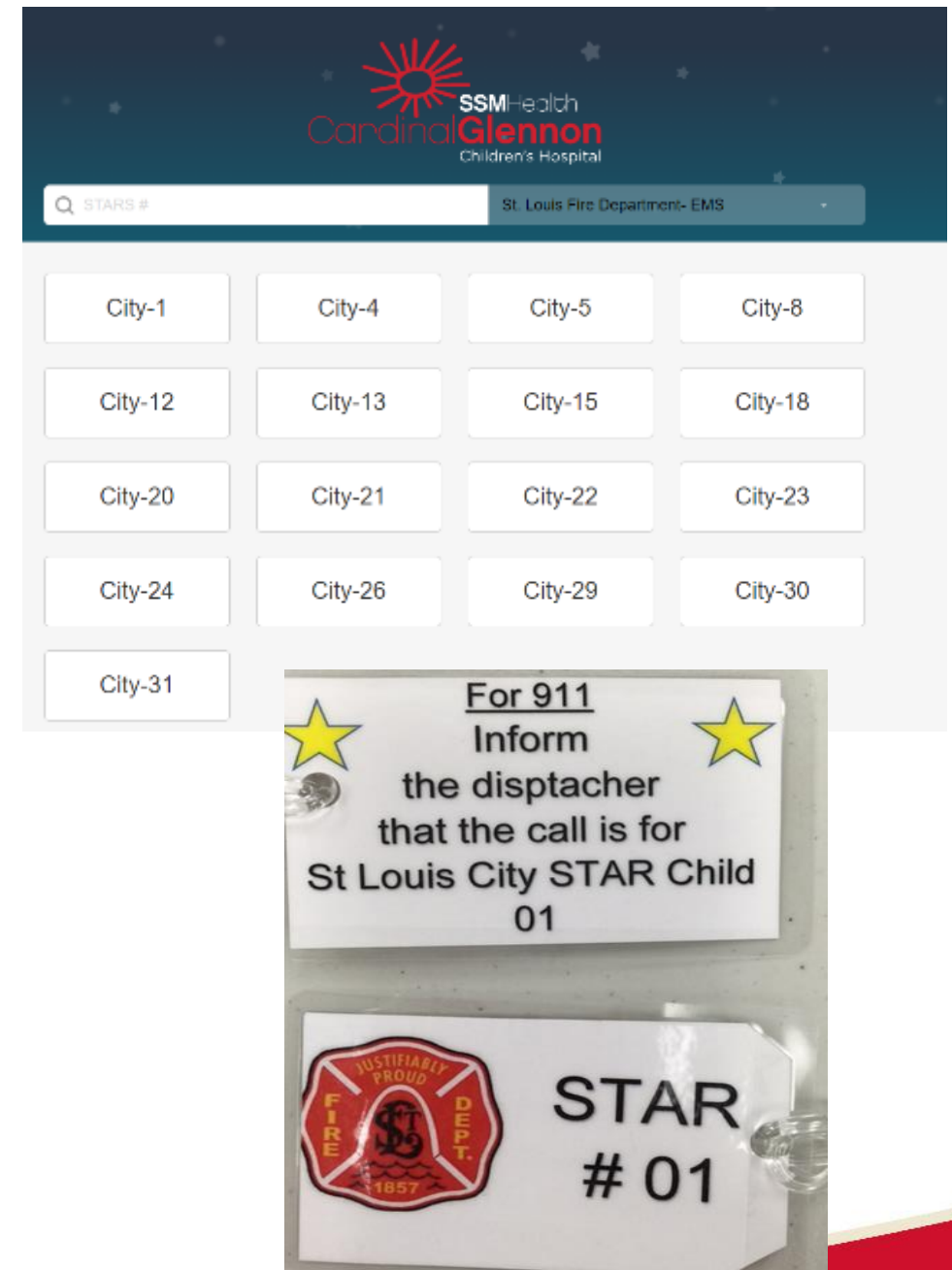
- **Fragile children are sent home with medical equipment and challenges that EMS providers and emergency departments are not prepared for.**
- **Home caregivers of special needs children are instructed to call 911 if the child becomes unstable which has resulted in poor outcomes.**

EMS Pitfalls

- Possibly limited to closest hospital
- Misinterpretation of assessment findings
- ****Taught to rely *completely* on caregivers**
- Lack of field appropriate advanced directives
- Specialty letters may not be followed
- Emergency medications such as steroids and clotting factor may not be given.
- Response times

What *is* STARS?

- Each child is assigned a unique “STARS #”
- Information is housed in a database that can be accessed by EMS, 911 Dispatch Systems and Community hospital Emergency Departments.
- Training intensive
- Plans are designed for EMS and Community ED use.
- Information is provided *prior* to an emergency taking place, and at the time of emergency dispatch.



Accessing for an Emergency?		Yes	No
47-4	M 1 y	HR	BP
	Attachments	R	SpO2
		TEMP	
		130	102/74
		32	>95%
			97.6

DIAGNOSIS

1 Propionic Acidemia (Metabolic Disorder)

***see letter under attachments**

Symptoms of PA crisis include: diarrhea, vomiting, lethargy, rapid breathing, decreased LOC, stroke-like symptoms & seizures.

2 History of SVT

3 Seizures

4 Hx of Metabolic Stroke

BASELINE FINDINGS

Alert, happy and interactive at baseline. babbles and turns his head to his name. Skin should be well perfused and warm with brisk capillary refill times. Pt. should have clear lung sounds and normal work or breathing. does have some mild hypotonia- please provide support to the trunk, neck and head at all times.

ANTICIPATED EMERGENCIES

1 Vomiting/ General Illness

At risk for dangerously high ammonia levels and acidosis if intake is stopped. Dehydration & hypoglycemia MUST be avoided. See treatments below and consider IV Zofran.

2 D10 @ 1.5 Maintenance Rate should be established with illness. *Administer via g-tube if unable to obtain IV access

(15 drops/min. with a 60 drop set =1.5 Maintenance for 10kg weight) If IV access is unobtainable, D10 may be connected to G-button attachment. If attachment is not available, the CATHETER ONLY (no needle) from a 14g IV can be used to access button

3 ED Staff Notes - see letter under attachments

fluid needs to be changed to D10 1/2 NS with 20meq KCL at 1.5 times maintenance upon hospital arrival.

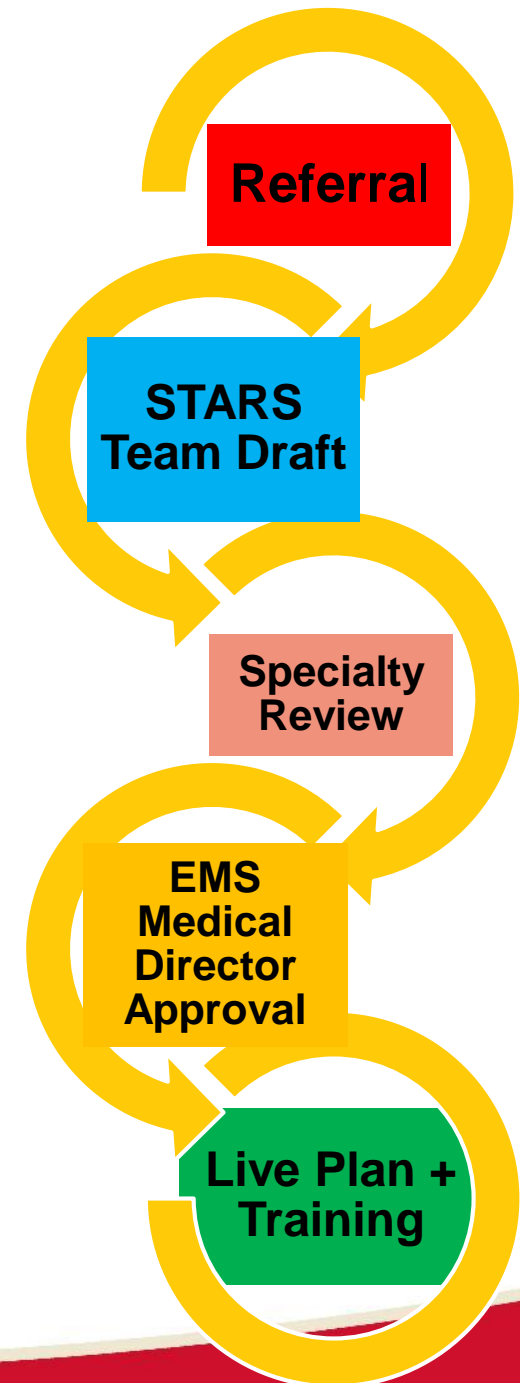
CAUTIONARY NOTES

1 Failure to treat symptoms of PA crisis may result in death

2 EMS: DO NOT STOP FEEDS

3 Hypoglycemia must be avoided

If pt. is ill or is lethargic, initiate D10 as documented even if pt.'s blood glucose level is found to be within normal range.



A True System

- Database driven
- Webinar trainings
- Quarterly meetings with coordinators and medical directors
- Representation at the regional and state level
- Education in paramedic programs
- Training Symposiums

Don't be scared of my airway,
it's not so bad!

1

**My Trach is the problem until proven otherwise!
It can easily become plugged or dislodged and that's
a life threat. This is my airway we're talking about!**

Check patency and placement.

**Make sure to check under the drain sponge or any skin folds in case
the trach has slipped out of the stoma.**

2

Supplemental O2 and Increased Support

**If I'm on a ventilator, work with RT or consult my primary hospital for
assistance. Remove me from the vent and assist with bag to trach if needed.**

**If I'm not on a vent, you need to remove any cap that may be on my tube
before giving me supplemental O2.**

3

Am I Improving?

**If the suction catheter would not freely pass, or I am continuing
to decline, I need an emergency trach change immediately! Ask my
caregivers to assist if they are available. I should have an extra trach
tube in my 'go bag' as well as a smaller one, just in case!**

Step by Step

Trach Change Instructions:

First of all, relax!

**My stoma had to be fully healed before I ever came home with my trach. I also have
it changed routinely at home by my caregivers as a part of my normal care schedule.**

- 1** Deflate the cuff first if I have one.
- 2** You can use an ETT directly into my stoma, if you absolutely have to.
- 3** Lay me back with my neck exposed, unfasten my ties, gently remove the old
one then immediately replace it with a new tube. Remove the obturator, fasten
my ties, ventilate and assess.

Helpful tips:

- Have my caregivers assist. They've done this many times.
- Using a towel roll under my shoulders may help with positioning.
- Lubrication can come in handy.

If you have difficulty recannulating:

- First and foremost, stop and ventilate me by other means if possible.
- If my "go bag" is there, try my smaller-sized emergency trach tube.
- If all else fails, use a smaller ETT in my stoma.

Rules:

Please listen to my caregivers.

They have been trained in both routine and emergency tracheostomy care.

**I must have working suction with appropriately sized French catheters at the bedside at
all times. Someone who is trained in emergency tracheostomy care must be with me at all
times. Even if you transfer me out, the EMS crew must be trained, or my caregiver has to be
with me. My 'Go Bag' is essential too. I shouldn't go anywhere without it!**

Remember!

When in doubt, change it out!



 **SSM-Health
Cardinal Glennon**
Children's Hospital.

 **SLUCare**
Physician Group

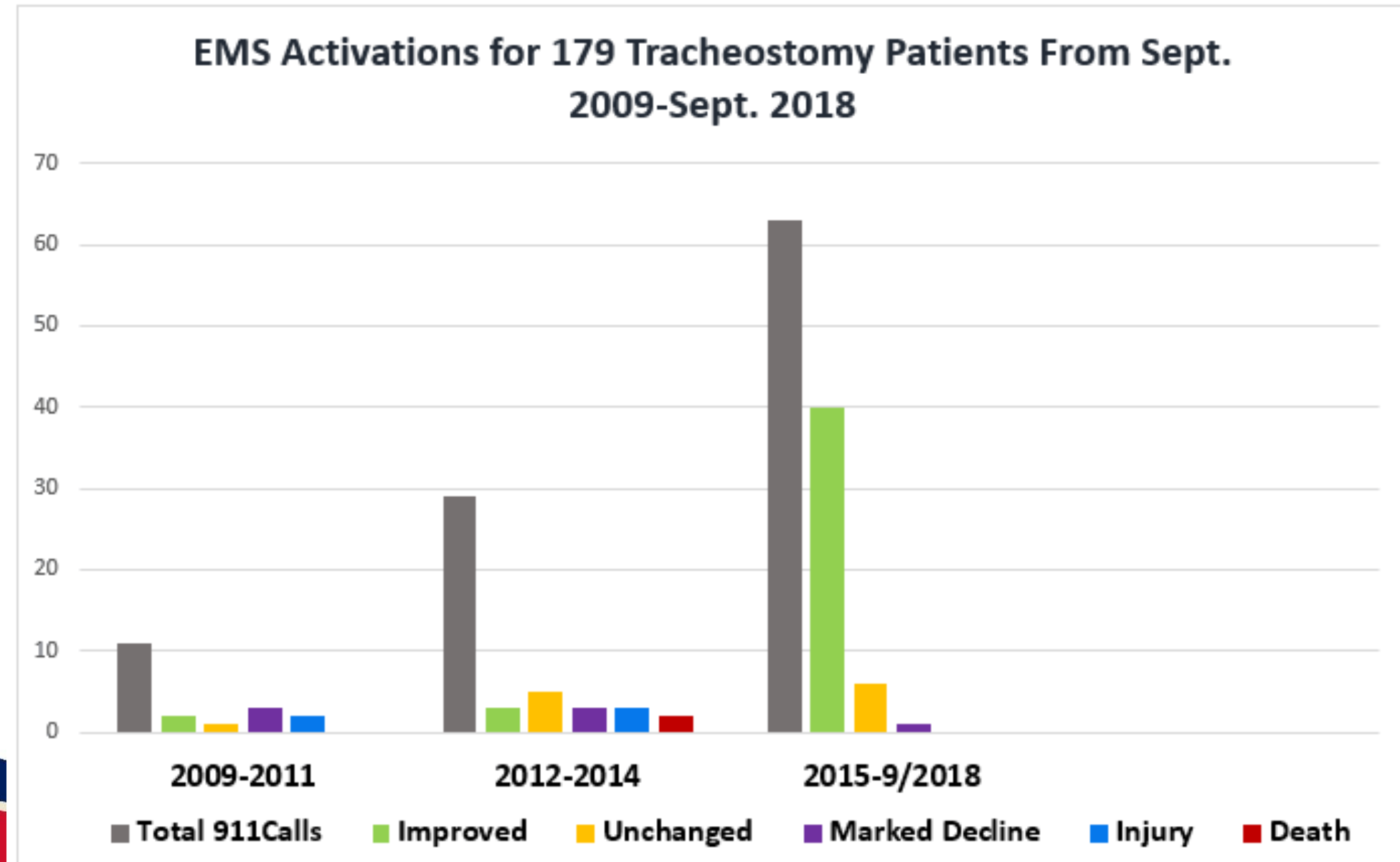
cardinalglennon.com/STARS

Field Deficits

- In 2016, 62% of St. Louis area paramedics reported via anonymous survey never having had formal training on tracheostomies.
- A 2018 survey of mixed providers nationally resulted in 60 % reporting never having had formal training on emergency tracheostomy care.



Results



Risk Factors

- Unfilled home nursing hours
- Inexperienced home health
- Being mainstreamed in school without a personal/ specialty trained 1:1 nurse
- Home environment
- Home location



Who's a STAR?

- **Tracheostomy and home ventilator dependence**
- **Cardiac History**
- **Home hospice or with specific end of life plans**
- **Uncontrolled or atypical seizures with specific seizure plans**
- **Metabolic and Mitochondrial Diseases**
- **Those with home medications for emergencies**



Communication is Key

- 911 Dispatch Centers
- Ground ambulance services
- First Responders
- School staff
- Community Hospitals
- Air medical
- Tertiary Emergency Department
- Specialty transport team



Where's the easy button?

*Identify



* Educate



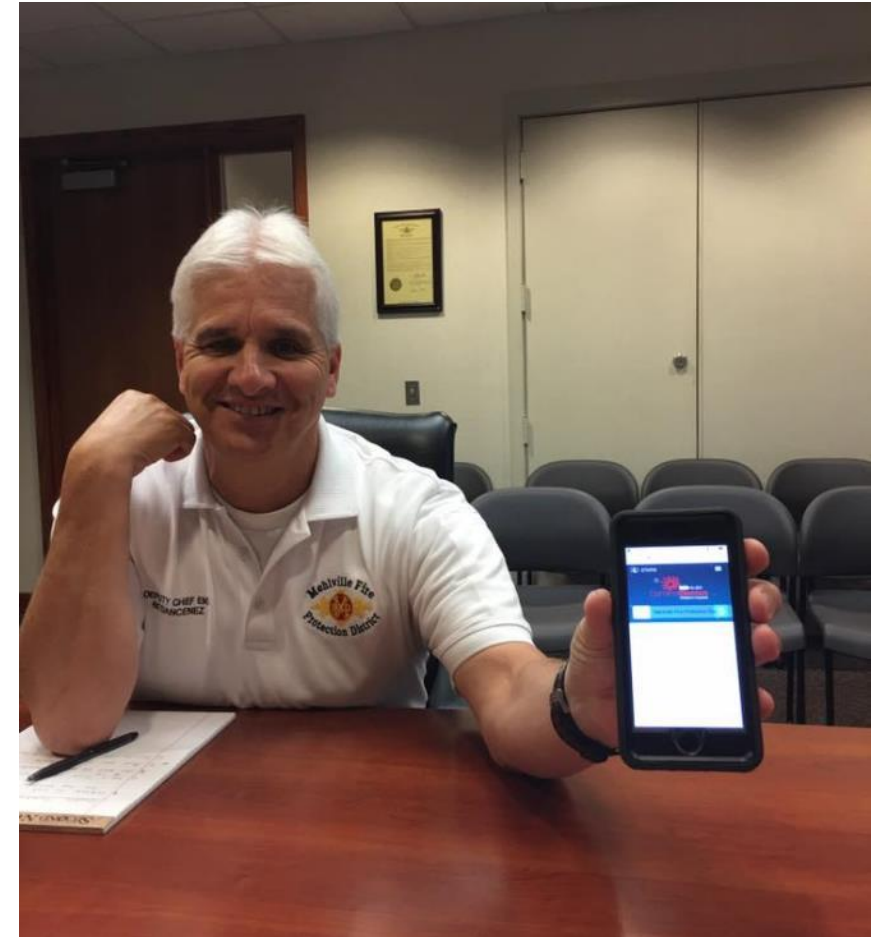
*Prepare & Share





Trials and Tribulations ; What we've learned

- Dedicated Team
- Continuous Updates
- *Set qualifications
- Continuous Training
- Metrics are a must
- **Database or disarray**



Because One Kid Counts



Patricia.casey@ssmhealth.com

www.Cardinalglennon.com/stars

References

- Sacchetti, MD., A, Sacchetti, C., Carraccio, C., & Gerardi M. (2000, Nov 7). The Potential For Errors in Children with Special Health Care Needs. *Academic Emergency Medicine*, 7. Retrieved from <http://pedsinreview.aappublications>
- Official American Thoracic Society Clinical Practice Guideline: Pediatric Chronic Home Invasive Ventilation
- Sterni, Laura et, al. (2016, Jan) An Official America Thoracic Society Clinical Practice Guideline: Pediatric Chronic Home Invasive Ventilation
- Dr. Steven Laffey, Professor of Pediatrics, St. Louis University School of Medicine, Director of ED Clinical Operations, SSM Health Cardinal Glennon Children's Hospital



Be like
“Missouri” and “Minnesota”!
Create a solution!





Bring together stakeholders :

State EMS, Advisory Physicians, Dept of Health, Legislators, Patient Advocates



Steps To Take:

1. **Examine your actual state protocols & regional regulations**
2. **Pole your own personnel and their perceived understanding**
In Missouri, ~93% of services contacted would not have administer patient-carried specialty meds in a crisis situation
4. **Partner with us, Danny's Dose, plus families to learn the issues**
5. **Establish needed legislation and amend regulations/protocols**
6. **Developed specialized education for emergency personnel**
7. **Build relationships with your affected families & create "Treatment Plans"**



Why is this so important?

*Our little
“Heroes”
currently are not
protected!*

*Our families live
in fear!*

*Lives are being
lost!*

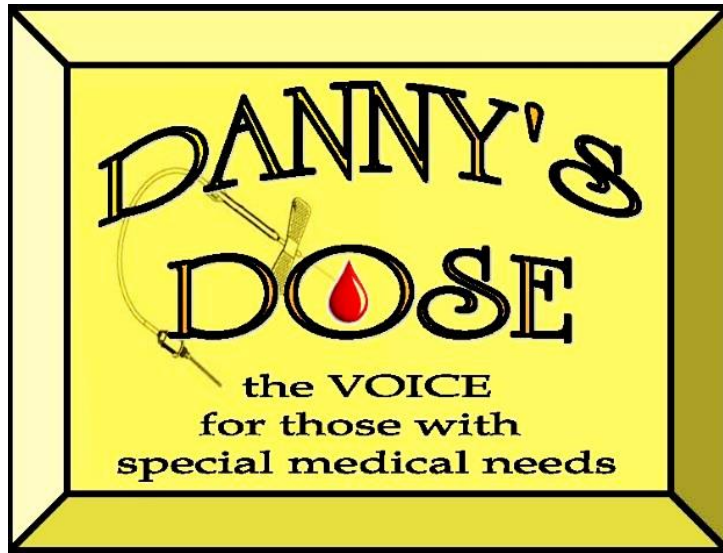


We are here to help & working on solutions!

- *Development of disease specific, standardized treatment protocols*
 - *Nationally recognized, CEU accredited, rare and chronic disease education*
 - *Template legislation*
 - *Template Treatment Plans*
- *Emergency Preparedness Education for families*
 - *Providing Emergency Alert items for families*

We are building alliances with stakeholders!

- *National and State EMS including: HRSA, EMSC, NAEMT, NAEMPS, NASEMSO*
 - *Many rare & chronic disease groups including: NORD, Global Genes, Every Life*
 - *Top specialist in the US for numerous conditions*
 - *A multitude of patient families ready to do their part*



Darlene Shelton
President/Founder

Email: darlene@dannysdose.com

Phone: 573-820-2819

Brian Froelke, MD, FACEP
Assistant Professor Washington Univ

Email: brfroelke@wustl.edu

Phone: 314-362-4362



Patricia Casey, EMT-P
STARS Program Coordinator

Email: patricia.casey@ssmhealth.com