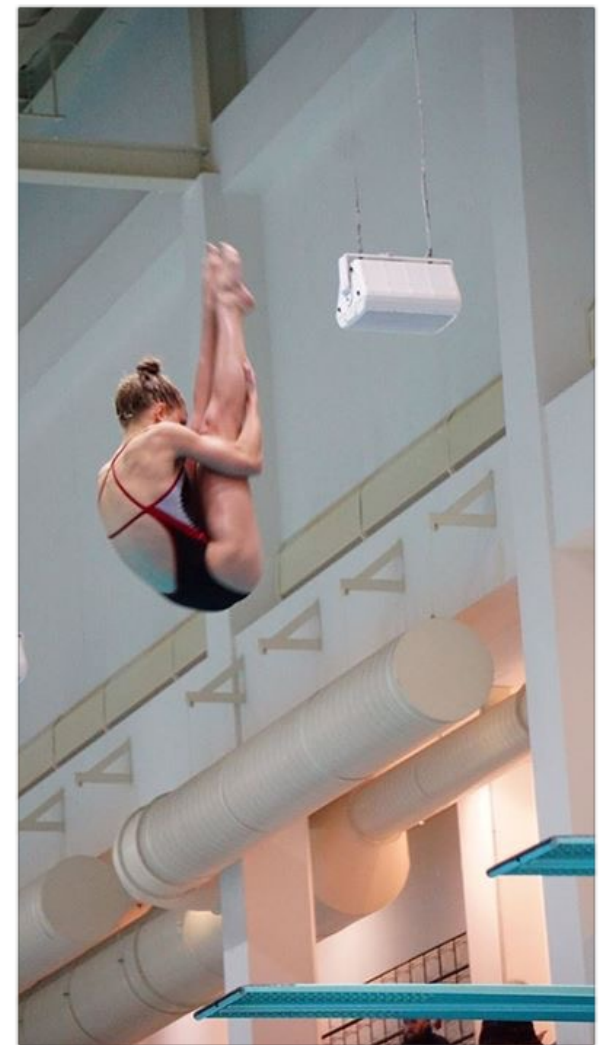


We Will Continue Your Fight



Christina Tournant
1997-2015



Dysautonomia (POTS): Christina's Story
Christina Elizabeth Tournant
June 24, 1997- March 5, 2015

Christina thrived and embraced life from the beginning.

She had an amazingly positive impact on people from a very early age.

As I wrote in 1999, a month before her second birthday:

***“You make other people feel special-like they matter to
and are important to you. This is a special gift. Truly
everyone you meet loves you because of your smiley,
winning way. You are such a ray of sunshine.”***

This was her most important gift...but she had many others....

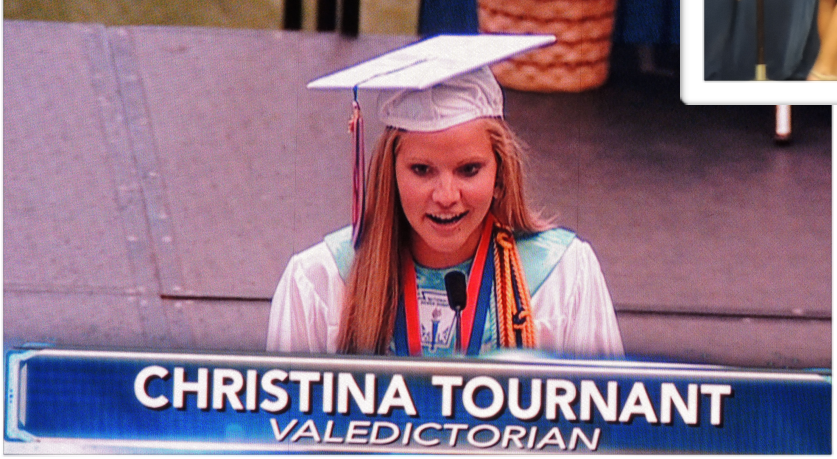
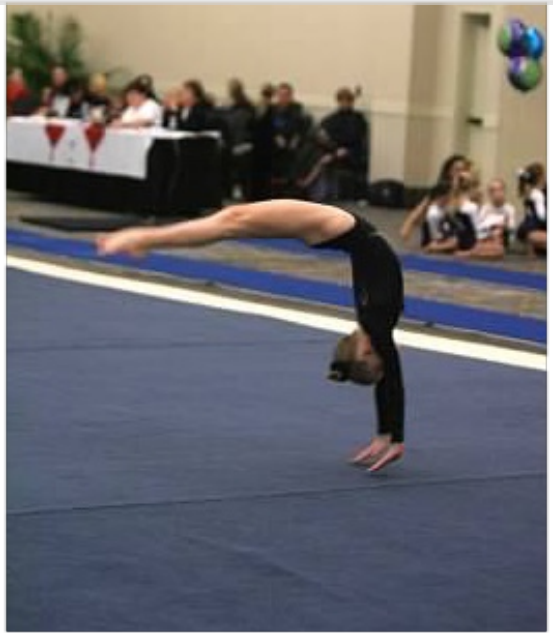


A Gifted Athlete:

State champion in gymnastics (ages 7, 8, and 9) and top-level competitive cheerleader.
Learned swim strokes as a freshman, yet qualified for state championships junior & senior years.
Captain of the track team and qualified for the state championships (300 meter hurdles).
Swam for M.I.T. until POTS took its toll and then began diving.
Everyone who coached her said she had incredible heart, drive, and work ethic.

A Dedicated Scholar:

Valedictorian amongst a class of 421.
Perfect score on the math section of the S.A.T.
Numerous state and local achievement awards.
Acceptance to her dream school, M.I.T.!



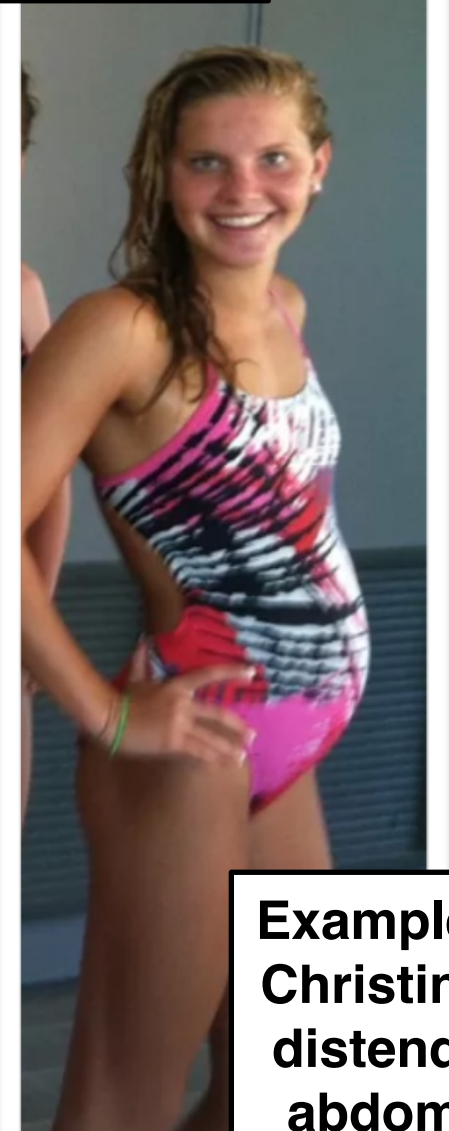
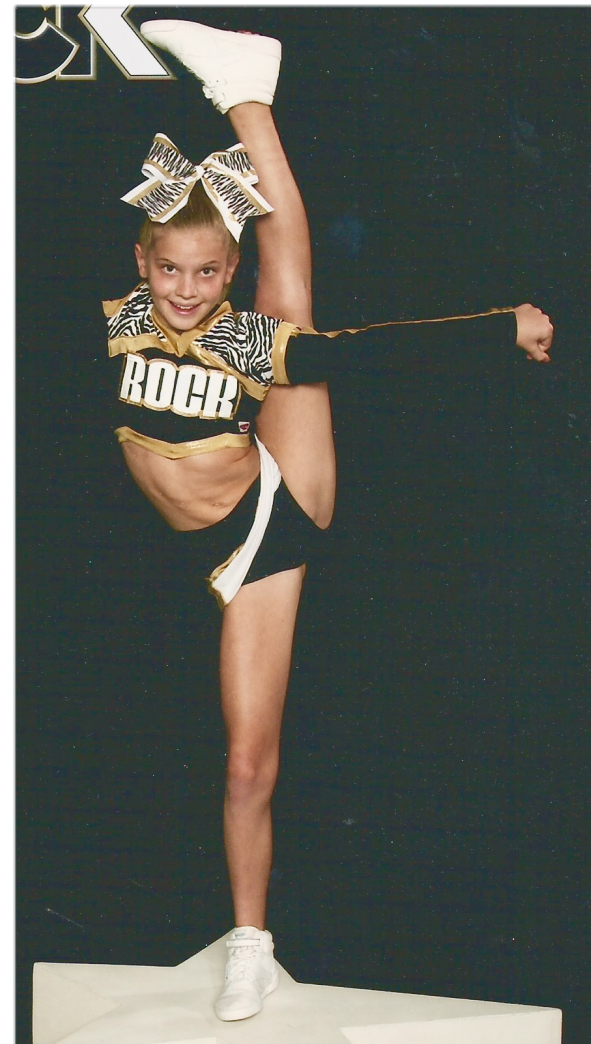
Early Medical History

Infant asthma age 5 months
High susceptibility to infections(103.5 degree fevers)
Rotavirus (3 day hospitalization) age 3
Diagnosed with hypohydrosis as a young child
Joint problems (ankles, knees, hips)
Hyper-mobility in feet, toes, elbows, scapula, and fingers
Benign tumors removed from femur and patella
Gastrointestinal problems from the beginning of her life (1st GI trip to ER at age 10: Diagnosis IBS)
2 Documented Concussions, ages 11-12



Age 14-15 & Onset of Menses: Symptoms Progress & More Dr. Visits

More gastroenterologists
Neurologists (joint pain, brain fog, severe headaches, trembling/twitching eyes)
Ear-nose-throat doctor
Psychiatrist
Kinesiologist (first medical professional to suggest problems were stemming from a malfunction of the autonomic system).



Example of Christina's distended abdomen

From Bad to Worse: October 2013 & Mononucleosis

- Worsening digestive symptoms/weight loss
- New symptoms:
 - Eye tremors
 - Ringing in the ears
 - Numbness of the extremities
 - Continuing fatigue
 - Dizziness
 - Becoming overwhelmed with too many sounds or noises
 - Joint pain (particularly in the lower back and hips)

- Years of Dr. visits and no diagnoses
- No Dr. took the time to see Christina as a whole person and try to understand systemically what was happening to her
- ***Not knowing why she was experiencing all the pain, discomfort, and other unusual symptoms, was by far worse than ANY diagnosis would have been.***



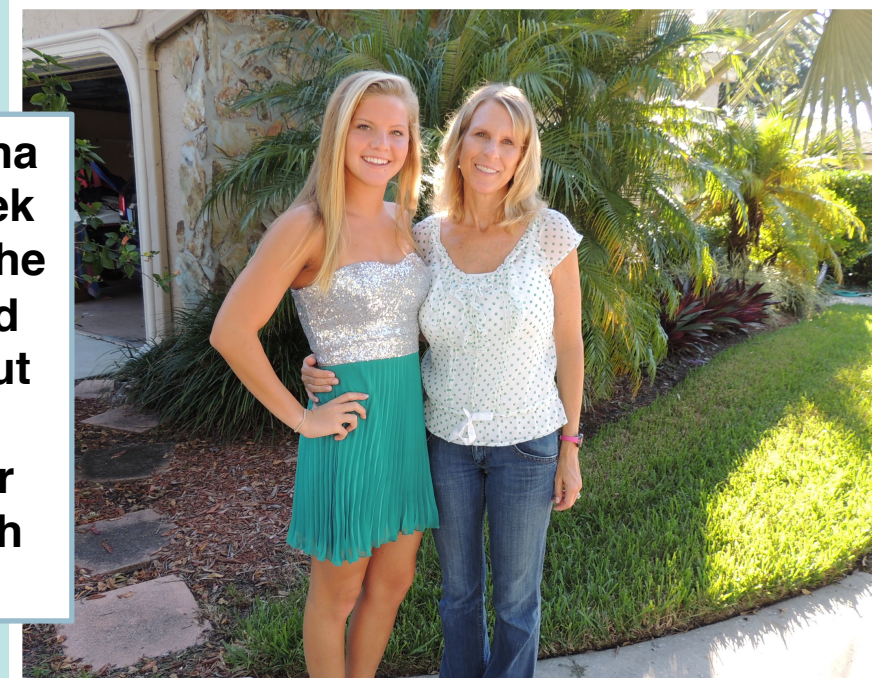
Looking good but
feeling terrible,
Spring 2014



In spite of
her
discomfort,
Christina
pushed
herself to
enjoy life.



Here Christina
was one week
into Mono. She
didn't attend
the event, but
wanted to
dress up for
pictures with
friends.



- Friend tells me about POTS, January 2014
- Gastroenterologist and other Dr. visits yield few answers in spite of escalating symptoms

***Ulcerative Colitis Diagnosis:
Christina was so relieved
she screamed and cried in
the recovery room
(possibility of medicine?
hope?)***



Fall of 2013



Since having Mononucleosis in the fall of 2013,
Christina had gone from 127 to 105 pounds.



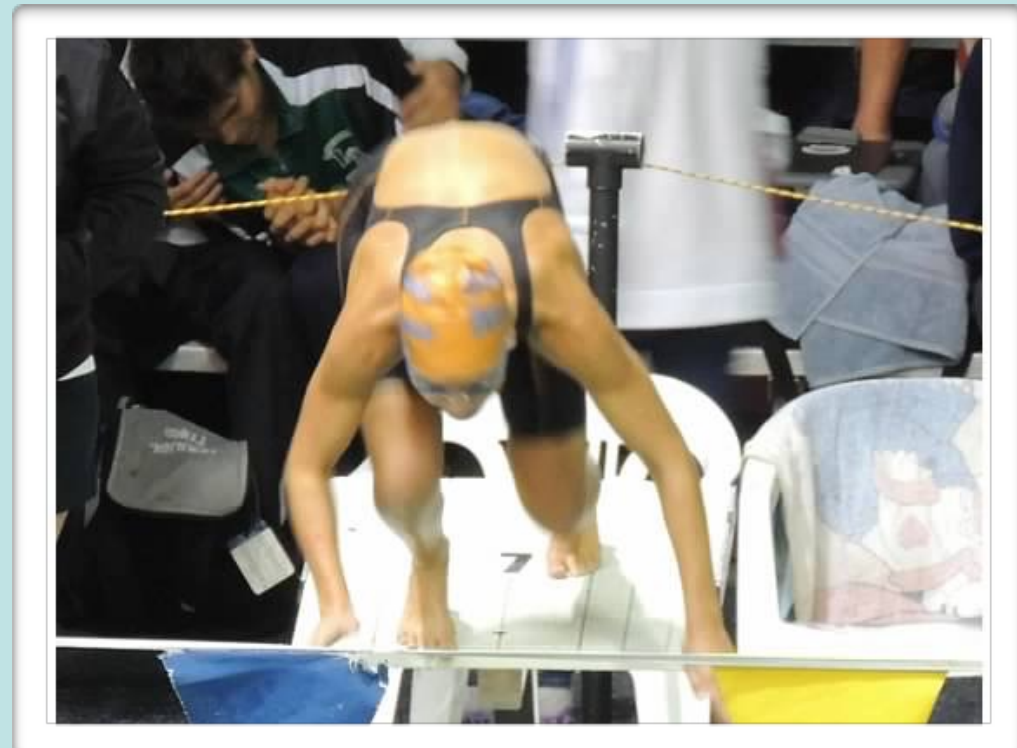
**Fall of
2014**

NOTE: Extreme concern about MIT

Pediatric cardiologist's diagnosis:

- **Official Dysautonomia diagnosis July 2014**
 - Dr. stated her case was mild
 - Dr. suggested that she would likely grow out of the symptoms and ***signed off on her NCAA paperwork to be a collegiate athlete.***

NO mention of the possibility of symptoms worsening, what to do if they did, and possible additional symptoms.



Three weeks in Boston

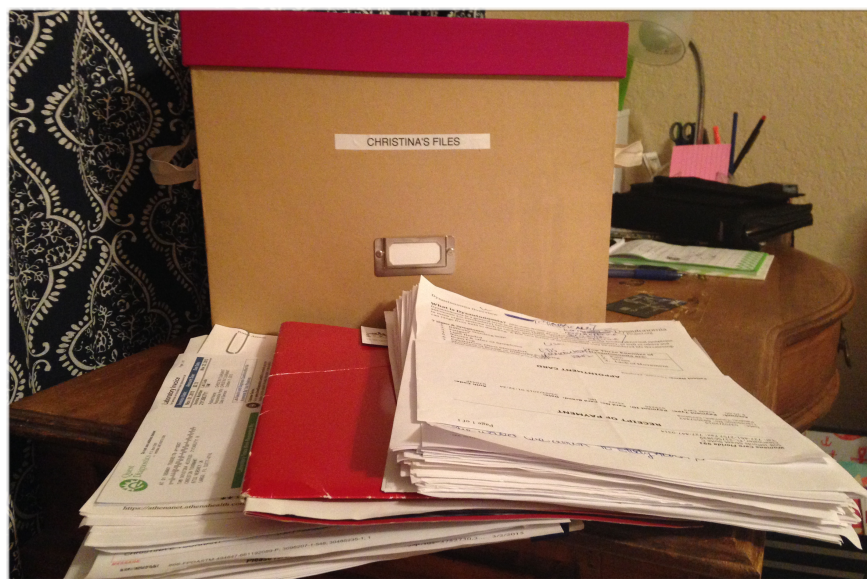
- Arranged for doctors/specialists and delivered pertinent records
- Ordered medications and foods



Christina's dorm



Christina and her roommate on the first day of classes at MIT.



Paperwork I had MIT Medical copy for her records (the box is full, in addition to the three additional stacks).



Christina with her baby brother in Cambridge just after starting classes.

Decisions from Christina's October visit home:

- Stop swimming and try diving
- Ease up on her restrictive diet

She had a lifting of her symptoms between mid-October and mid-December.

We were hopeful that the switch to diving, in addition to going back to a less restrictive diet, were helping her.



Photos framed in black were taken her second week of diving practice,
Photo framed in white was taken 3 months after she began diving



December/January Downward Spiral

- January 25th text: **“I think my body has kinda given up on me.”**
- Limited access to MIT medical
- February 17th: physical and emotional breakdown, and explanation of severity of her condition
 - New MIT medical appointments
 - Student services visits/medical withdrawal
 - New script and new doctor

In the waiting room of one of her medical appointments in March



Trying to look brave, days before her medical withdrawal



Sample of texting sequence between Jan. 17th and Jan. 25th

Yep! I competed out of my 12 dives 4 were new !
I did front two and a half somersaults on 3 meter

Text Message

Messages Christina Details

The meet was good I got the NCAA cuts!
So I'll be going to that regional meet

iMessage

OMG, that is amazing! Congratulations!

Text Message

I won both boards

Sun, Jan 25, 10:51 AM

Haven't been feeling very well recently, just slept 19 hours my body is kinda giving up on me haha. I will keep you posted as I try to move around today

Text Message

Upon Return to Tampa

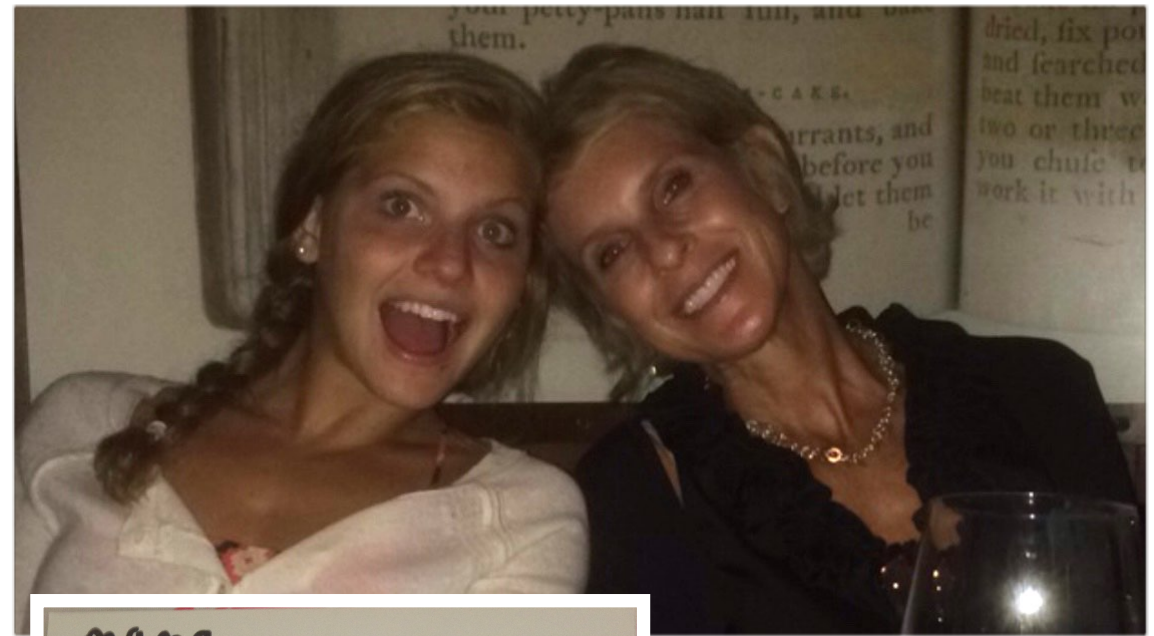
Visited:

- ENT doctor (sinus infection)
- Gastroenterologist (bloody stools)
- Gynecologist (more blood work and hormone testing)
- Psychiatrist
- Cardiologist

Plan:

Research out-of-state (POTS-specific) specialists while Christina heals from her infections (review findings on Friday, March 6th).

Christina jumped to her death on Thursday March 5th, 2015, with no hope that she would ever get better.



mama,
You are perfect
thank you for
being my best friend.
love you to pieces
sorry I couldn't
keep fighting.
Love,
Your full on
dweeb

Christina wrote on the back of this picture to me...It was found, along with others, in the car she drove to the airport.



How I am Continuing Christina's Fight

- Working with Dysautonomia groups to spread awareness among physicians, other medical professionals, and the public
- Participating in Dysautonomia-related fund raising efforts
- Responding to inquiries from families struggling with their diagnosis and daily life with POTS

If just one of the many physicians and specialists we saw along our journey had known about POTS, Dysautonomia, or EDS, Christina would have been diagnosed years sooner.

THANK YOU for being here today!

