

## Abby Vogts joins FUSE Board!

The FUSE Foundation Board of Directors is pleased to welcome Abby Vogts to the Board. Abby has been a FUSE



volunteer from the beginning, and served as a key member of the medical staff for the

2010 Retreat. Abby is a native of McPherson, Kansas, and graduated from Washburn University in Topeka. She now lives in Olathe, and works in Topeka at Stormont-Vail as an ICU nurse. Abby's passion for FUSE is obvious, and we're happy to have her join our leadership team.

A special congratulations to Abby, as she'll be marrying Taylor Bauer on October 15th!

**A huge THANK YOU to Zach Mohr for his service on our Board!**



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## Learning about Stem Cells First Hand

On Saturday, June 18th, FUSE friends had the opportunity to learn first-hand about the experience of receiving a stem cell treatment, and hear of the changes that have resulted in the lives of three young men:

- Byrum Bittel, 15, of Spearville
- Ian Conner, 22, of Wichita
- Ryan Benton, 25, of Wichita

Each of these men have Duchenne Muscular Dystrophy, and each have undergone stem cell treatment through the Cell Medicine Institute in Panama City (formerly in Costa Rica). While their stories have much in common, each experience has been unique.

Byrum has had one treatment (October 2010), and already sees improvement in his overall stability. He will have another muscle biopsy in a few months. Ian has had one treatment (June 2009), and has experienced improvements in his breathing, weight stabilization, and increased strength

in his neck. Ryan, after four treatments, has seen the most dramatic change, including weight stabilization at a healthy level, and improved coordination and strength. Most notably, Ryan's most recent muscle biopsy indicated "normal" levels of Dystrophin. His prior biopsy (which confirmed the diagnosis of Duchenne), showed NO Dystrophin.

The treatment is somewhat painful, and expensive at this time, but it's clear that it holds much promise for patients with Duchenne, and likely many other neuromuscular diseases. Work is underway to achieve FDA approval for the treatment, which would make it available to many others. For now, this treatment is not available within the United States. More information about the Panama clinic is available at [www.cellmedicine.com](http://www.cellmedicine.com).

THANK YOU to each of these young men for sharing their stories with FUSE.

*there is*  
**HOPE**



Byrum, Ian & Ryan



**RECOGNIZING  
FUSE  
ACHIEVEMENTS**

*Congratulations on your recent graduation:*

**AARON NIEDHART,**  
Dodge City  
Community College

**BROOKE ZIEGLER,**  
Wichita State  
University

**BRITTANY DECKER,**  
Wichita State  
University

**GABE PARHAM,**  
Friends University

**SAMANTHA  
THOMAS,** Wichita  
State University

*Congratulations,  
also, on these recent  
achievements:*

**ERIN WILLIAMS,**  
passed the Board  
requirements and  
is now a Registered  
Dental Hygienist  
(RDH)

**DEVIN BOX,** enjoying  
his new job with  
Dillon's in Derby

**BRUCE VINES,**  
completion of the  
CISCO Certification  
Program

**VOLUNTEER  
UPDATE:**

**Thursday, August 11 through  
Sunday, August 15  
Camp Tawakoni, near Augusta**



**COULD IT BE ANY MORE FUN THAN THIS?**



It's almost time for FUSE Retreat! That's a phrase that elicits mixed emotions -- EXCITEMENT and FUN for some, PANIC and CONCERN for others. With such a great group of campers and volunteers, though, there's no doubt that this will be the best Retreat ever.

The schedule for 2011 includes many popular features from years' past, including fishing, the fire pit, the coffee house, karaoke, the dance, the awesome food. But, for 2011 there are NEW events, too! There's a revision to the "amazing chase" for this year, plus the special visit from **Serena's Song** (see photo). This HUGE hot-air balloon is wheelchair accessible, and will be visiting this year's FUSE Retreat to provide rides for everyone! How exciting!



Here's the story of **Serena's Song**:

The balloon is named for Serena, now 25 years old, who suffered complications during birth. When she was two, her father Gary Waldman received an invitation to give Serena a ride in a hot air balloon. Her reaction was priceless! Up until then, Serena was emotionless and unable to speak; indeed, Gary was uncertain how much of the world his daughter was absorbing. But as the balloon soared upwards, Serena screamed with delight. It was then that Gary decided to commit his life to re-creating that experience for other persons with disabilities. He contacted Phil Gray owner of National Ballooning. Phil's heart went out to Gary and his dreams. It was without hesitation that Phil decided to design and engineer the world's first special-needs accessible aircraft. When asked why did you do it, Phil replied "Everyone should have the opportunity to experience flight."

**2011  
RETREAT  
PREVIEW**

**"Old Standby" events  
plus NEW SURPRISES  
at 2011 FUSE Retreat!**

**PAPERWORK NEEDED  
ASAP!**

*If you haven't submitted  
your application for  
RETREAT, we need it  
NOW! Contact Terri  
Reed at 620-242-8153  
for more information.  
You won't want to miss  
a minute of this year's  
Retreat!*

**CONGRATULATIONS** to volunteer TY JOHNSRUD on recently completing his first Triathlon. And special thanks to Ty for promoting FUSE on your jersey! You're awesome!







# FUSE GOES (to see the Wichita) WILD!

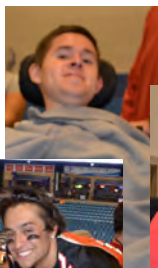
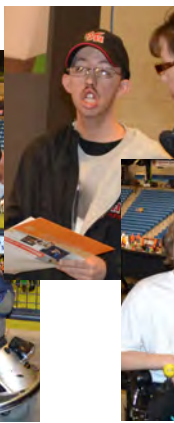
After a fun time watching the WILD in their 2010 season, we were anxious for a return visit! On April 16th, more than 20 FUSE friends met at Hartman Arena north of Wichita for a fun night of football. It was great to

catch up with everyone, enjoy a spirited game (man, it moves fast!), and watch an awesome half-time performance from two area high school Drum Lines.

Following the game, two of the players joined our group to sign autographs and snap some pics. They don't seem nearly so mean when they're OFF that field! It was indeed a WILD time!



*WILD Quarterback Shane Mascarenas happily signed autographs following the game.*



*The FUSE visit brought good luck to the WILD with a big win over Amarillo.*

## WINTER JAM & FOOD!



On February 27th, FUSE enjoyed great food & drink at the River City Brewery before heading to the Intrust Arena for an awesome concert - "Winter Jam"!

## Annual Fundraising Campaign Rocks Along...

A huge THANK YOU to those FUSE friends who continue to bless our organization with their financial support. Our annual "letter campaign" is a pretty low-key campaign, but has given us consistent financial support for our events.

Just so you'll know, we'll accept tax-deductible contributions at ANY time, and have also been honored to receive several memorial contributions. If you have

any questions about the "business" side of The FUSE Foundation, please contact our

Treasurer, Robert Neidhart, at the address or e-mail on the back of this newsletter.

If you've already responded to our campaign, THANK YOU! If

it hasn't been the right time for you, just keep watching your mail, 'cause we'll be back again!

FUSE FOUNDATION FUNDING from annual Letter Campaign

2009	\$14,160
2010	\$ 9,750
2011	\$ 7,195

*Thank you for your support!*



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## Upcoming Events

- 2011 FUSE Retreat, August 11-15, Camp Tawakoni  
The highlight of the year!
- What next?  
Let us know what YOU want to do. Another event will be scheduled before the end of 2011, so where do we go?



## Ideas for future events?

FUSE Foundation events are provided to fulfill our Mission -- *empowering through educational opportunities, support and social networking*. If you have event ideas, contact any Board Member. We'd love to hear your thoughts!

## OUR MISSION

To facilitate an inter-dependent community of young adults with neuromuscular disease, that empowers through educational opportunities, support and social networking.

## BOARD OF DIRECTORS

Terri Reed, President  
 Chad Yeager, Vice President  
 Robert Neidhart, Treasurer  
 Teri Russell, Secretary  
 Abby Vogts

CONTACT US AT THE ADDRESS ABOVE WITH ANY QUESTIONS!