

What would we do without Robert?

Every great organization has that special person who just "takes care of things". At FUSE, we're very fortunate to have



Robert Neidhart! Robert has served as Treasurer for the

FUSE Board of Directors since the beginning, including all the technical paperwork for establishing the Foundation. He quietly takes care of our finances and any required reporting, all while working a (more than) full-time job as an Accountant in Dodge City, and being a pretty terrific dad and husband.

We have a lot of great people who volunteer with FUSE, but Robert is EXTRA special, and we're so thankful for all his contributions.

Thanks also go to the entire Neidhart family for sharing Robert with us! Marty, Peter and Aaron -- you're a lucky bunch!



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Retreat 2011: Up, Up & Away!

Retreat 2011 featured tons of fun events, great food, plus the AWESOME experience of soaring above Camp Tawakoni in Serena's Song -- a HUGE hot air balloon, specially designed for handicap access. The weather made things a little difficult (imagine that in Kansas!), but eventually cooperated, and all who wanted to ride were able to.



This year's retreat was made even better by the addition of several new friends from throughout the state -- we almost doubled in size this year!

Other retreat highlights included great presentations by Nick Taylor and Nick Ferrell, a terrific concert/dance with Tin Cup Monkey, fun at the pool, some creative and entertaining acts for the Open Mic show, hot competition in our first-ever "Minute To Win It" games, and so much more.

One challenge was the continuing hot, dry weather, which kept us from fishing or boating -- but we're hopeful for next summer! Mark your calendars now -- don't miss out: **August 9-12, 2012!**



RECOGNIZING FUZE ACHIEVEMENTS

Our FUZE friends are having LIFE-CHANGING events:

ABBY VOGTS married **TAYLOR BAUER** on October 15th in McPherson. They make their home in Olathe.

ERIN WILLIAMS married **SETH COHEN** on August 5th (just missing the 2011 Retreat!). They make their home in Overland Park.

SAMANTHA THOMAS and **JOE JARVIS** eloped on September 30th. Joe is currently deployed in Afghanistan. They'll renew their vows and have a reception on March 30, 2013.

TY JOHNSRUD married **ELISABETH SHORT** on October 10th. Ty and Elise now live in Kansas City.

MORE TO COME: **LAUREN RUSSELL** and **CHRIS MILLER** will be married on September 29th (provided they survive Retreat 2012)!



Ian Conner receives ASTYM treatment on his neck from Sandy Hopp-Edwards at the FUZE Retreat

WHY PHYSICAL THERAPY?

by Sandy Hopp-Edwards, P.T.
and Charissa Ahlstedt, O.T.R. of
ContinuCare LLC, McPherson

Physical and occupational therapy treatment goals are to enable muscular dystrophy patients to reach their maximal physical potential. Goals include prolonging independence, slowing progression of complications, and improving quality of life.

PHYSICAL THERAPY:

Therapies include stretching, strengthening, breathing exercises and performing modified daily living activities. Training is also included for the use of adaptive equipment, such as wheelchairs, walkers, and home modifications. Some treatments can also help with pain, maintaining muscle length, and body positioning (bracing, wheelchair modifications). Another treatment, ASTYM (Augmented Soft Tissue Mobilization), can restore lost range of motion allowing increased movement and function.

Stretching and strengthening of all joints may help keep the body flexible,

upright, and as mobile as possible. The three main areas for contractures (loss of flexibility in joints) in the legs include the heel cords, hamstrings, and hip flexors.

Bracing may be recommended to keep joints in appropriate position to allow mid-line posture and function. Bracing can offer joint support as muscles lose strength.

Avoiding curvature of the spine with adaptive positioning and appropriate seating helps control neck and back pain, and makes daily living activities easier.

Breathing problems can be caused by inappropriate positioning, asymmetrical use of the body, and contracture of the body. Strain on the lungs frequently occurs with the curvature of the spine. Exercise in the pool helps with breathing activities and increased endurance for independent mobility.

OCCUPATIONAL THERAPY:

The goal of OT is to improve quality of life. People with muscular dystrophy have the potential for decreased mobility and strength, postural instability and possible contractures. OT focuses on maintaining or improving mobility of the upper extremities (emphasis on elbow, forearm, wrist and fingers) to allow use of the arms for daily tasks and leisure activities.

Occupational Therapists assist individuals in learning or re-learning self-care skills, improvement of arm or hand functioning, more effective use of computer skills, bathroom use and other daily life tasks. They can also assist in the development of social skills, employment opportunities, leisure, and home modifications.

For more information, talk to your physician or local therapist, or contact ContinuCare at 620.241.1825 or continucare@yahoo.com.

Physical Therapy and Occupational Therapy may be options to help improve the lives of anyone with muscular dystrophy.

"We believe the ASTYM therapy is so important that we make the 5 hour round-trip every three weeks. This treatment has kept Dalton more independent and able to enjoy his activities."

- Stacy Black, mother of DMD patient

FUNDRAISING UPDATE:

Our 2012 FUZE Fundraising letter campaign will begin next month. If you're not included on our mailing list, and would like to be, just contact us at the address on the back of this newsletter. Or, if you know of grants or matching funds that could be available for FUZE, please let us know! We have a wonderful group of supporters, but the need continues to grow. Thanks for your support!

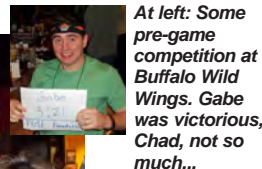


FOOD, FUN & NEW FRIENDS!

What a great way to spend St. Patrick's Day! The FUSE group gathered in Wichita for pre-game nourishment at Buffalo Wild Wings, then traveled to Intrust Arena to watch the Wichita Thunder take on the

Arizona Sundogs. It was an eventful and close game, but the Thunder prevailed! Lots of fun for the entire group of 30+. A definite highlight was Chad's (failed) attempt to conquer the "Blazing Wings" challenge at

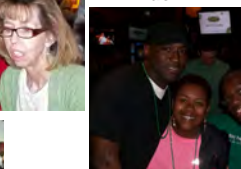
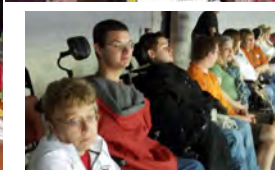
BWVs. He WAS successful in guilting Gabe into joining him, though, and Gabe was victorious. We're not sure Gabe felt like a "winner" the next day, though! Always a fun time when FUSE gets together!



At left: Some pre-game competition at Buffalo Wild Wings. Gabe was victorious, Chad, not so much...



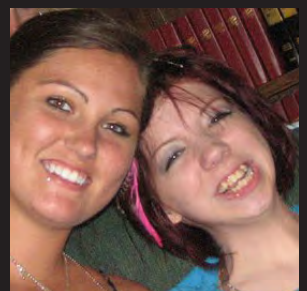
The FUSE visit brought good luck to the THUNDER with a win over the Arizona Sundogs!



Kayleen Sabala (far right) joined us for her first FUSE event! Welcome Kayleen, family & friends!



RETREAT ROOKIES!

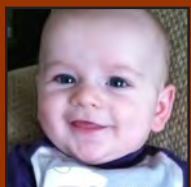


Retreat 2011 included a great group of "Rookies" -- first-timers! We're pretty sure they're hooked now, too! Welcome to FUSE!

FUSE Family Continues to Grow!

A special welcome to our newest FUSE-ers:

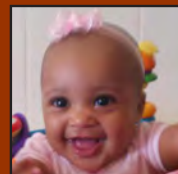
AYLA JOY YEAGER, born November 30, 2011, to FUSE Board Member Chad & (Volunteer) Sarah Yeager in Topeka. Ayla joins big brother Drake as the next FUSE generation.



GRAHAM DOUGLASS JORGENSEN was born November 3, 2011, to FUSE volunteers Cody & Rachel Jorgensen in Overland Park. Graham is sure to learn the FUSE ropes quickly from cousins Drake & Ayla!

Welcome PRESTON DALE & ASHLYNNE GREY, twin niece and nephew of FUSE member Breanna McCully. These special kids were born July 16, 2010, and were joined by their new baby sister OLIVIA KATHERINE on January 19, 2012. Aunt Bre couldn't be prouder -- totally understandable!

JACQUELINE ELLEN, cousin to Sarah Smith, was born on Halloween 2011. Baby Jacqueline will be well-known to the FUSE family thanks to Sarah's amazing Facebook skills!



Welcome all!



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Upcoming Events

- 2012 FUSE Retreat, August 9-12, Camp Tawakoni

The highlight of the year!

Applications available June 1st -- don't make us wait for yours! Get it all done early and start planning for a great time!

- **MYSTERY EVENT!**

Planning is underway for an event in the KC/Topeka area before Retreat - watch Facebook for more information!



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 Bauer

CONTACT US AT THE ADDRESS ABOVE WITH ANY QUESTIONS!