Olivia Goldring, age 16, and her younger brother, Jason, age 10, lost their mother to FTD in February 2012. Rachel Goldring, who was diagnosed with FTD eight years prior, was just 53 years old. For Olivia and Jason, and presumably for many young children with a parent affected with FTD, “growing up” happens at a much faster rate than it should. Childhood is a bit lonelier, too.

But the good news is this: children who face these kinds of losses often possess a remarkable quality—resilience. Olivia and Jason are no exceptions.

To honor the memory of her mother, Olivia decided to engage the school that she and Jason attend, the Salt Lake City conference. The conference will be held at the Salt Lake Marriott Downtown at City Creek. Please visit AFTD’s website for online registration and complete details about the Salt Lake City conference.

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Spotlight On... Bonnie Shepherd, AFTD Board of Directors

Like many others, Bonnie Shepherd’s first step in her journey to AFTD started with her spouse’s FTD diagnosis in 2007. At that time, Bonnie had very little information about FTD and felt like a “deer in the headlights” while trying to understand the disease. Bonnie did her own research through online resources, and that’s when she discovered AFTD.

After realizing that AFTD existed and served as a valuable resource to affected families, Bonnie and another caregiver, whose husband had been diagnosed with FTD, started a support group in Utah in 2007. The meetings bring together those who have loved ones affected by FTD and helps people understand they are not alone in their struggle. Oftentimes, the group provides a resource for advice and comfort. Bonnie continues to lead the support group in Utah.

While attending a national FTD conference at Northwestern in 2011, she was able to meet and get to know some of the AFTD staff. She shared her story and desire to become more involved with AFTD. In 2012, Bonnie accepted the invitation to become a member of AFTD’s Board of Directors. She cited AFTD’s organizational skills, the excellent staff and board members along with the dedication that everyone had to their work as the reasons she decided to join the board.

Bonnie has brought to the board a passion in fighting this disease as well as personal experience. She was instrumental in having AFTD recognized in Utah as a member of the Utah State Task Force for Alzheimer’s. “Not only is it important for there to be awareness for family members with FTD, but also doctors and healthcare providers to be aware of FTD. In rural parts of Utah, this is difficult,” said Bonnie.

Recently, Bonnie has been a tremendous contributor in helping to organize AFTD’s upcoming education conference in Salt Lake City on April 12. Bonnie has played a vital role for this conference as she has acted as the person “on the ground” for AFTD. She has helped identify and organize speakers, and continues to work with the venue around planning and coordination.

Bonnie has been a valuable addition to the board, and she is excited about the future of AFTD. “Not only is raising money in order to conduct research important, but the ability to educate family members, the community and doctors is vital to the future of AFTD... the quality and dedication of the staff and the board members to their work makes this possible.”

AFTD News Briefs

There are new FTD support groups in the following locations: Winston-Salem, NC and Woodburn, OR. Check AFTD’s website for a complete listing of support groups.

AFTD knows how difficult the physical and emotional demands of caregiving can be. The Comstock Caregiver Respite Program provides $500 grants to full-time family caregivers for respite. More information and the application form are available on AFTD’s website.

AFTD, Northwestern’s CNADC and the National Aphasia Association will present three continuing education webinar trainings in PPA for speech-language pathologists beginning May 1. Details on AFTD’s website.

Are you considering volunteering with AFTD? Do you want to learn more about our current opportunities? AFTD has launched a new page on our website for the Volunteer Program. The page highlights volunteer opportunities such as fundraising and media outreach, and recognizes standout volunteers. If you want to help make a difference and get involved, complete the volunteer information form found on the webpage. Check it out!

AFTD is accepting applications for its 2013-2014 Pilot Research Grant. Applications are due July 1, and the grant will be awarded on October 1. Visit the research page of AFTD’s website for more information.

For those who would like to “give back” to AFTD, the organization has teamed up with Capital One to offer an AFTD credit card. A percentage of each purchase made with the card will be donated to AFTD by Capital One. Turn those everyday purchases into a meaningful gift to AFTD. Check AFTD’s website for program details.
AFTD Names Postdoctoral Fellow: M. Catarina Silva, Ph.D.

AFTD has named M. Catarina Silva, Ph.D. as its Postdoctoral Fellow for 2013-2015. Dr. Silva, who is training in the laboratory of Stephen Haggarty, Ph.D. at Massachusetts General Hospital, emerged at the top of a field of 18 candidates from 12 different institutions, all vying for a single, two-year award. “The quality of applicants and projects gets better every year,” noted Carol Lippa, M.D., who led the committee of scientific reviewers from AFTD’s Medical Advisory Council (MAC).

“We had an extremely difficult time deciding among the top four candidates, any one of whom AFTD would have been proud to fund.”

Dr. Silva received her Ph.D. in biochemistry and molecular genetics from the University of Lisbon in Portugal and Northwestern University in the United States. In a scientific procedure developed just six years ago (and for which Shinya Yamanaka, Ph.D. received the 2012 Nobel Prize in Medicine) Dr. Silva will be using tissue from skin cells of actual FTD patients to create Induced Pluripotent Stem cells (IPS cells) that can be used as a disease model in the laboratory. She will study these IPS cells as they develop in the lab in order to gain a better understanding of the step-by-step process that occurs in disease development.

The AFTD Postdoctoral Fellowship is designed to identify a promising young researcher at the start of his or her career and provide support for their work in the laboratory of a scientific leader. The hope is that by the end of the two-year fellowship, the individual will have acquired both valuable experience and key data in an FTD-related project, and be able to garner broader support that will lead to a successful career in FTD research.

Goldring (continued from page 1)

Riverdale Country School in Riverdale, New York. She approached Riverdale with the idea of a walk-a-thon to benefit AFTD in memory of her mother at the elementary school. This was the first time a student-led extracurricular activity was proposed and approved by Riverdale. And once approved, Olivia and Jason went to work.

The 11th grader created and distributed a fact sheet about FTD and what it means to her family. She also designed a sponsor sheet for the young walkers to use in gathering pledges from their family members and friends. Jason helped create excitement about the walk at school.

When October 27th, rolled around, all 500 of the elementary students and faculty participated in the RCS 2012 Walk-a-Thon for Rachel held during the school day at the tennis courts and ball field. The four- and five-year-olds collected pledges for each lap that they walked around the tennis courts. The older students walked around the ball field to earn their sponsorship dollars.

Olivia and 10 of her friends also participated in the event. Jason spoke to the school at the walk-a-thon. “AFTD is extremely important to my family. I was really little when FTD struck my mom, and they were there to provide information, resources and guidance to my dad. We’re thankful for the organization and your participation in this walk to support it,” said the 10-year-old fundraiser.

Olivia was astounded by the enthusiasm and generosity of the elementary school. “It was really awesome to see all the kids—even the smaller ones—walking and participating. They were all excited and happy to take part. It was a great event and a great day,” she said.

A few days after the walk-a-thon, Olivia emailed the Riverdale Country School community to thank them for supporting the Goldrings’ cause. “They were all so giving, so willing…just because they wanted to. That meant so much, and I had to thank them for that,” said Olivia.

When everyone had collected their pledges, the school had raised over $8,000 to support the mission and work of AFTD.

“I am so proud of Riverdale,” said Olivia. “I’ve learned that amazing things can be accomplished when people pull together for a collective effort. And I’m grateful for their support of this walk honoring the memory of my mom.”
FTD and The Alzheimer’s Drug Discovery Foundation (ADDF) have announced the award of three grants under their joint FTD Drug Discovery program. The 2013 awards, which total $430,000, support scientists investigating three different disease mechanisms at work in FTD: reduced levels of the protein progranulin, the C9orf72 mutation that causes both FTD and ALS, and dysfunction of the cellular pathway that normally clears damaged proteins from the cell.

Under the partnership agreement ADDF pledges to match AFTD’s contributions 2:1, however this year ADDF contributed an additional $130,000. “The projects were especially high quality this year,” said Diana Shineman, Ph.D., director of scientific affairs at ADDF. “We are learning more and more about the common pathways underlying different neurodegenerative diseases and are pleased to be providing more funding for research that will hopefully pave the way toward effective therapeutics.”

The first grant was awarded to Nigel Cairns, Ph.D. of Washington University, St. Louis, who has identified two compounds that elevate the level of the protein progranulin in cellular and animal models of disease. He will conduct studies that will help determine how each of these compounds can be modified to maximize their potential as drugs to treat individuals who develop FTD because of low levels of progranulin, including people who have inherited a mutation in one of their progranulin genes.

Another award went to Jeff Rothstein, Ph.D., M.D. at Johns Hopkins University in Baltimore. A leading ALS researcher, Dr. Rothstein’s work will focus on the newly discovered C9orf72 mutation, which causes approximately 11% of FTD, 30-50% of familial ALS, and up to 10% of sporadic ALS, making it the most common known genetic cause of FTD/ALS to date. Dr. Rothstein’s goal is to use a technique that has been successful in other neuromuscular diseases caused by similar mutations, called antisense oligonucleotide therapy (ASO). An ambitious project, this approach has potential to produce both a therapeutic to counteract the C9orf72 mutation and a biomarker that would measure the efficacy of ASO therapeutics in clinical trials.

The final award was made to W. Haung Yu, Ph.D. of Columbia University in New York. Dr. Yu’s work is aimed at a fundamental pathologic process underlying most neurodegenerative diseases: abnormal buildup of proteins which leads to the death of the nerve cells, or neurons. Dr. Yu’s past work has been the study of the cell’s natural system to clear out these clumps of nonfunctional proteins, called autophagy. In this project, he will synthesize compounds designed to support and enhance the cell’s natural autophagy pathway, with the hope that they might be used as drugs to clear abnormal protein accumulations before cell death occurs. Although Dr. Yu’s initial work will be with tau (which is found in Alzheimer’s and FTD) subsequent studies will assess whether the same compounds are effective in clearing aggregates of other proteins, such as TDP-43 and FUS (seen in ALS and FTD) and synuclein (found in Parkinson’s disease).

This is the sixth year of the FTD Drug Discovery program, which is designed to stimulate the translation of knowledge gained in the laboratory into the clinic in the form of potential therapeutics for FTD. To date, the joint program has awarded 22 grants totaling more than $2.3 million. Prior years’ awards have laid the groundwork for at least two clinical trials in FTD and related diseases.

“ADDF continues to be a wonderful and generous friend to our community,” said AFTD Executive Director Susan Dickinson. “We are proud to join with them in supporting excellent science that will benefit our families.”

Stem cell research holds much potential in learning more about FTD.
Your Gift This Spring Goes Triple the Distance!

Every dollar you give to AFTD for Drug Discovery this spring will be matched 2:1 by our partners at the Alzheimer’s Drug Discovery Foundation (ADDF). Your donation will help us move toward finding care and a cure.

This is the 6th year of the FTD Drug Discovery program, which is designed to stimulate the translation of knowledge gained in the laboratory into the clinic in the form of potential therapeutics for FTD. To date, the joint program has awarded 22 grants totaling more than $2.3 million. Prior years’ awards have laid the groundwork for at least two clinical trials in FTD and related diseases.

Your past support has been vital to making forward progress in the area of drug discovery. Please join us in the pursuit of finding care and a cure by financially supporting our efforts in drug discovery by making your donation today.

To make a gift, please visit our website at www.theaftd.org

Food for Thought Event in Philadelphia
Save the Date!

Join AFTD’s staff and board of directors for the culmination of “Food for Thought” week at Susanna Foo in Radnor, PA on October 11!
Details to come...see Food for Thought article on page 10!
Donations Honor Loved Ones

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AFTD is grateful for these gifts, which fund research, education and support.

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Susan Diana Watson
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Janice Pellegrino Weitzell
John E. Wilhelm
David Zomback

In lieu of flowers...

Families who wish to direct memorial donations to AFTD are encouraged to call the office. AFTD can mail you donation materials, or you can download them from the AFTD website. All donors will receive letters of acknowledgment, and families will receive a list of donors. To contribute electronically via our website, go to www.theaftd.org.
Imagine a world where doctors quickly identify the quirky ways of someone with behavioral variant FTD (bvFTD) and do not automatically assume they are seeing bipolar disorder or depression. Imagine speech pathologists who understand they cannot approach the language loss of someone with primary progressive aphasia (PPA) in the same way they address someone who has had a stroke. Imagine nurses, caregivers and directors of residential care facilities who are not intimidated by a new resident with FTD. Imagine what a world of informed healthcare professionals would mean to a family coping with how FTD has changed their lives.

That vision, a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented, is spelled out in the AFTD mission statement. Now, with several AFTD achievements, including recent additions to the AFTD website and some well-placed AFTD initiatives, there is significant progress toward achieving it.

With the input of the AFTD Medical Advisory Council, 24 of the foremost leaders in FTD research and clinical management, AFTD has expanded their website pages that target healthcare professionals. Now, medical practitioners and specialists can find information about the clinical features of FTD and references for the most current diagnostic criteria for bvFTD and PPA. An overview of pharmacological treatments will be added by March, and archived educational resources will be added as they are developed to increase the value of the site as a resource of FTD education for professionals.

“We don’t envision that our website will be the only resource for physicians and community healthcare professionals,” said Sharon Denny, AFTD program director, “but we want to provide a comprehensive overview of information where they can find links to a wealth of other resources.”

AFTD took another step by collaborating with the National Aphasia Association (NAA) and Northwestern University’s Cognitive Neurology and Alzheimer’s Disease Center (CNADC). The result is an education coalition that will reach out to speech and language pathologists to help them understand and improve treatment approaches for patients with PPA. The group is planning a series of three accredited webinar trainings, the first of which will be presented in May by Sandra Weintraub, Ph.D., director of neuropsychology at the CNADC, who will present a clinical overview of PPA.

Reaching into the world of psychiatry are AFTD Medical Advisory Council members Edward (Ted) Huey, M.D. and Chiadi Onyike, M.D. Though not officially representing AFTD, they will present a short course for psychiatrists at a meeting of the American Psychiatric Association to be held in San Francisco in May. AFTD Executive Director Susan Dickinson also will be among the presenters.

Getting the word out to treatment program managers and community providers is a major piece of the outreach initiative. In January, AFTD Program Director Sharon Denny and AFTD Long-Term Care Education Committee Member Sandi Grow, RN provided web training for the National Adult Day Services Association (NADSA). Forty program administrators and staff from across the country attended the live training and others will have access to the archived recording.

“It was very well received,” reported Teresa Johnson, NADSA managing director. “The expertise from both a professional and also a family caregiver with a nursing background provided a lot of credibility to the information. They shared with us effective treatment methods that our participants can use right away. We were delighted with how well done it was.”

An ongoing program is Partners in FTD Care, launched in 2011 to educate the staff and management in home health, assisted living, nursing care and adult day and hospice programs. The program generates in-service materials including a quarterly e-newsletter featuring case studies to help practitioners build knowledge and confidence in serving people with FTD. It is a product of the AFTD Long-Term Care (LTC) Education Committee, which is comprised of nurse educators, social workers and caregivers.

Members of the LTC Education Committee also collaborated on an article on FTD for the Journal of Gerontological Nursing. The article, entitled “Managing Differences: Care of the Person with Frontotemporal Degeneration,” was co-written by two committee members, Nurse Practitioners Jill Shapira, Ph.D. and Geri Hall, Ph.D. with Mariabeth Gallagher, DNP and Sharon Denny, M.A. Published in March, it emphasizes the challenges of caring for people with non-Alzheimer’s dementias in general and FTD in particular and uses case examples to illustrate common features of bvFTD and PPA.

“These efforts are examples of how building and leveraging relationships with our medical advisors and committee members can impact our ability to educate health professionals about FTD,” said Denny. “We have much more to do but we have made great progress.”

*Contributor Elaine Rose is a writer and caregiver to her husband with FTD.*
AFTD Unveils a Booklet for Those Newly Diagnosed

The doctor says the exam results point to a diagnosis of frontotemporal degeneration (FTD), and the prognosis is not good. Come back again in 6-12 months.

A bit simplistic perhaps, but this general scenario describes how most families are introduced to FTD. They are given a clinical diagnosis and left to research it further on their own. One caregiver equated it with being set adrift on the open sea in a very small boat with no compass, oars or provisions.

A new publication from AFTD seeks to change that. Available in April, *The Doctor Thinks It's FTD. Now What?* provides a strategic approach to learning about the disease and managing care.

“We hope every physician will give this booklet to patients when they deliver an FTD diagnosis,” said Susan Dickinson, AFTD executive director. “Families deserve support right from the start.”

The booklet reflects the cumulative experience of thousands of individuals and families who have faced a new diagnosis of FTD and the professionals who work with them. It distills AFTD’s experience into the following five elements that should be addressed early and revisited over the course of the disease. Learn about the disease, identify your care team, address legal and financial planning, develop daily structure, and assess safety issues. A two-page checklist and list of key resources are also included. The considerations and practical steps are equally applicable for spouses or partners, individuals diagnosed with FTD, or extended family and friends.

“No one becomes a caregiver overnight,” said Matt Sharp, AFTD program coordinator. “This approach will provide guidance for people to lay a solid foundation on which to build skills and confidence over time.”

AFTD will distribute introductory copies of the booklet to medical centers, FTD support groups and key volunteers. Individual copies are available for free through the AFTD website, and bulk orders can be placed by clinics or organizations for nominal fees.

Giving a Hand to Our Helping Hands!

AFTD volunteers are a special group of people, and we appreciate everyone who has taken action and become involved. A passionate, flexible and committed volunteer since 2009, Angela Kimble recognizes the significant role she plays as an AFTD representative in her Houston community. And she’s made a huge impression among many.

“Angela is always willing to take on new projects quietly behind the scenes,” said Susan Eissler, AFTD board member and south central regional coordinator. “She is doing a lot for AFTD and the FTD community in Houston.”

Angela discovered AFTD after her mother’s FTD diagnosis began to progress rapidly. She was in search of support and others who could relate to her circumstances and understand. Angela was surprised to learn that although she was living in the 4th largest city in the country, there was not an FTD support group in her area. After her mother was placed in a facility and stabilized, Angela had the emotional strength to start a support group, which will be three years running in April, alongside her co-facilitator, Chris.

Angela also played a vital role participating in the development and implementation of AFTD’s new outreach initiative to bring awareness to facilities. She helped establish the process and develop the volunteer tools, and she was also one of the first volunteers to initiate facility visits. Angela works tirelessly towards establishing and maintaining professional relationships on behalf of AFTD. She is already beginning to plan for her next project, which will be an AFTD fundraiser in the fall.

By getting involved, Angela feels empowered. When her mom was facing so many challenging symptoms, Angela felt like she had no control over the situation. However, by volunteering she feels she has found some solid ground to stand on. She gets excited and motivated by initiating new AFTD projects and educating people about FTD. Through her participation as a volunteer, she is hoping to make a difference for her future and for that of her children.

For anyone interested in becoming a volunteer, Angela stresses the importance of being in the right place emotionally, thinking it through before getting involved and making sure the right supports are in place. AFTD is grateful for Angela’s dedication and passion. She has impacted the lives of many. Thank you, Angela!
Awareness: AFTD Presents “Food for Thought” Campaign

Has the idea of raising public awareness of FTD been simmering in your mind? Have you considered doing a fundraiser to support research or AFTD’s mission but have had too many things on the burners to make it happen? Or maybe you’ve done these things in the past and are hungry to help out again? If so, put the first week of October on your calendar—we’ve got something cookin’ that you definitely want to be a part of!

The first week of October, AFTD will launch its first-ever annual “Food for Thought” initiative. Food for Thought is a grassroots fundraising and awareness-raising campaign designed to rally as many supporters of AFTD as possible during the first week of October across the country and Canada. Our collective effort to raise awareness will hopefully draw the media’s attention and garner some great press about FTD.

As we all know, FTD is a life-altering disease for those affected as well as their loved ones. Yet it is little known and poorly understood. This campaign seeks to make a few more people aware of FTD while involving some food/drink and a little education. Event hosts can have a dinner in their home for friends and family, hold a bake/cider sale or engage a local restaurant to have a “Food for Thought” night out at their establishment. More details about each of these options can be found in the Food for Thought toolkit on AFTD’s website.

AFTD’s Food for Thought Goal: To have at least one person in every state and five people from Canada host a Food for Thought event! And as a little incentive, we’re throwing out a challenge: the state that hosts the most number of events will get a page on AFTD’s website dedicated to their Food for Thought stories for an entire year. Each organizer will get a picture and short write-up about their Food for Thought event…and bragging rights until next October!

So…are you hungry enough to take a bite out of FTD? Ready to join people from Connecticut to California to Calgary who will share a meal and provide some FTD education with their friends and family (and hopefully the media)? If so, we want to hear from you! Simply fill out the Food for Thought Event Form on AFTD’s website, and we’ll get an AFTD Food for Thought Volunteer Liaison in touch with you.

We’re looking forward to seeing what all of our voices together can do to raise awareness of FTD! Don’t get up from the table just yet…we have a great opportunity to make a REAL difference and draw national attention to FTD. And it will be awesome for you to be able to say, “Yeah, I was a part of that…and I’m here to Fight This Disease”

Together, we’re a recipe for success!

Advocacy: Rare Disease Day in Washington, DC

AFTD Program Coordinator Matt Sharp, along with advocates from around 150 other rare disease organizations, participated in the 3rd Annual Legislative Conference and Rare Disease Lobby Day. Sponsored by rare disease legislative advocates, the conference and lobby day were among the many events going on in Washington, DC during the week leading up to National Rare Disease day on February 28th.

The week’s happenings started on the evening of the 25th with the premier screening of the documentary film “Here. Us. Now.” Tuesday’s legislative conference was a full day workshop to prepare for the next day’s congressional office visits. On Wednesday the 27th, Matt, along with three other advocates from PA, visited the offices of Senator Robert Casey (D), and Representatives, Chaka Fattah (D PA-2), Tom Marino (R PA-10), Pat Meehan (R PA-7) and Jim Gerlach (R PA-6) to discuss the devastating consequences sequestration will have for rare disease research and to ask each of them to protect NIH and FDA funding and to become a member of the Congressional Rare Disease Caucus. Every legislator who spoke with AFTD representatives was against sequestration, yet all seemed resigned to its inevitability. On a positive note, everyone was at least interested in the Rare Disease Caucus, if not already a member. They suggested that despite the difficulties that will arise from the across the board budgetary cuts the sequester entails, members of congress are sympathetic to the needs of the rare disease community and willing to do what they can to help.
Robert Hartman Benefit for Research

The 1st Annual Bob Hartman Food for Thought Benefit for Dementia Research took place on November 10 in Philadelphia. Bob’s wife, Loretta, and his daughters, Ingrid and Audrey, organized the affair, which raised $2,588 for FTD research.

Paul Lester Raises $13,230 with Words

For the 6th year in a row, Paul Lester from Raleigh, NC, sent out more than 300 letters to family and friends, asking for their support of AFTD’s mission in honor of his wife, Arnette. In his most successful campaign to date, Paul’s efforts raised $13,230 for drug discovery research.

Three Woman Art Exhibit

Artists Lisa Schulte, neighbor to Moe & Stu Bryant, and Cyndee Howard donated proceeds from their exhibit featuring neon sculptures and photography from October 25-27 to AFTD. The show, entitled the Three Woman Art Exhibit, was held at the Heather James Art Gallery in Santa Monica, CA. The event raised $760 in support of AFTD’s work and much awareness of FTD. Below is a picture from the exhibit.

Another Marathon for Russell Zomback

Russell Zomback of New York ran his third marathon for AFTD on October 14 in Newport, RI. Running in memory of his father, David, Russell raised $2,607 for drug discovery.

2nd Annual Robert Hatfield Foundation Golf Outing Raises $6,000 for AFTD Research

The Robert M. Hatfield Foundation, Inc. hosted its 2nd annual golf tournament on October 25, 2012 in St. Petersburg, Florida. More than 50 golfers attended the event, which raised $6,000 for the AFTD. The Robert M. Hatfield Foundation was created in memory of Matt’s father, a lifelong golf enthusiast, who passed away from FTD in October 2010. Matt is pictured below, along with friends and fellow supporters, Adam Wides, Trevor Harris and Ryan McBee.

Musselman High School Girls Volleyball Team Takes on FTD

The Musselman High School girls volleyball team in West Virginia chose to raise money for AFTD in October in memory of Head Coach Shawn Martz’s father, who passed away one year prior from FTD. Shawn’s family has also lost two aunts and one uncle to the disease. The team eagerly took up a cause close to their coach’s heart. With a raffle for a variety of baskets, the team raised $1,896 to benefit AFTD’s mission. Pictured below is Musselman’s ninth grade volleyball team with the raffled baskets.