Ice Buckets Change How the World Looks at ALS

To say that we are grateful for the increased support and awareness from this summer’s Ice Bucket Challenge phenomenon, is an understatement. The ALS Association, including 38 nationwide chapters, is overwhelmed and humbled by what we have received. We send our heartfelt thanks to everyone who participated in the Ice Bucket Challenge and for making donations to support our fight against this horrific disease.

Ice Bucket Challenge FACTS:

- According to The New York Times, people shared more than 1.2 million videos on Facebook in the span of 45 days (July and August 2014) and mentioned it more than 2.2 million times on Twitter.
- Wikipedia articles on ALS grew from an average of 163,300 views per month to 2.89 million in August alone.
- The ALS Association announced in August that more than $115 million in donations had been received nationwide.
What was it like to be on the receiving end of the Ice Bucket Challenge? This is a question we get asked quite a bit. And it is a difficult question to answer. The Ice Bucket Challenge took over life, as we know it, at the ALS Association from July 29 through mid-September. It was, quite simply, fun, challenging, unprecedented and unfortunately something that is not likely to happen again. In the meantime it had a huge impact on ALS awareness and funding, not to mention an increase in the demand for our resources. With increased awareness comes an increased request for assistance and THANK GOODNESS we have the Ice Bucket Challenge dollars to help fill the increase in requests for help.

We have been given a GREAT gift through the Ice Bucket Challenge and we are treating this “one time” phenomena with the utmost respect and care, as well as thoughtful and strategic planning. The average cost of ALS on a single family –

Letter from the President - Eric Zydel

In past years when I have written this letter I have often expressed the feelings of gratitude for things that have transpired relative to the ALS Association and our mission, and certainly no exception. Unless you don’t have a television, don’t have access to the world of nonprofit fundraising or are an island, you are keenly aware of the notice that ALS has received this year. Driven by the passion of thousands, if not millions, of caring individuals and the magic of social media, the Ice Bucket Challenge has propelled ALS awareness and support to levels that we could only have dreamed of before.

This sensation has forever changed the way the world looks at, thinks about, talks about, and regards ALS. No longer is ALS the orphan disease that is overlooked and misunderstood as it has been for decades. Never in our history has ALS received such widespread recognition and support. We are an organization that has received $110 million in donations in less than a month. Never in our history has ALS been able to count on such widespread recognition and support as in this past month. Never in our history has ALS been able to count on such widespread recognition and support as in the past month. Never in our history has ALS been able to count on such widespread recognition and support as in the past month. Never in our history has ALS been able to count on such widespread recognition and support as in the past month.

Q: What is your connection to ALS?
A: My father was diagnosed with ALS in June 1978. He deteriorated fairly quickly because he had taken hold of his breathing. He was on a ventilator for a while but at his own request he wanted to die a natural death. The ALS phone number was the first “Walk to Defeat ALS” in the nation and set the national trend. We started something truly good here in Pittsburgh!

Q: What are you most proud of over the last 32 years?
A: I’m very proud that I’ve helped the Chapter grow. I’m really proud to see the organization become more professionally run and well organized. I’m proud to be a part of an organization like The ALS Association Western PA Chapter.

Q: What would you like to see happen?
A: I would like to see the money from the Ice Bucket Challenge go to ALS research. I would like to see the organization become more professionally run and well organized. I’m proud to be a part of an organization like The ALS Association Western PA Chapter.

Q: What do you believe is so special about the Ice Bucket Challenge?
A: I believe that the Ice Bucket Challenge was the first time in history that ALS was able to count on such widespread recognition and support as in the past month. Never in our history has ALS been able to count on such widespread recognition and support as in the past month. Never in our history has ALS been able to count on such widespread recognition and support as in the past month. Never in our history has ALS been able to count on such widespread recognition and support as in the past month.

Q: What are the reasons why people are interested in ALS?
A: I think that the reasons why people are interested in ALS are that they want to help the organization and they want to help the people who are affected by ALS.

Q: What do you think is the most important way to get people involved in ALS?
A: I think that the most important way to get people involved in ALS is through the Ice Bucket Challenge. People are interested in ALS because they want to help the organization and they want to help the people who are affected by ALS.

Q: What is your greatest hope for the organization?
A: My greatest hope is that we will find a cure and a cause for ALS or at least a treatment. I never thought back in 1981 that we would be still in the same position now that we were then.

Q: One of the things you did for the Chapter was make phone calls to our donors. Why do you believe that is so important?
A: I have donated to a variety of organizations over the years and one I had $40 per month withdrawn from my paycheck as a donation to them for ten years in a row. Nobody EVER called to thank me. I think that’s a pretty good indication of what they thought of my $40 a month. If someone had just called to say “thank you” it would have meant a lot to me. That’s why I think you can never thank people enough for the time that they put in and for the money they donate. People appreciate being thanked. Sometimes our donors are really surprised when we call them. They are surprised to hear from us.

Once again thank you for all that you have done and continue to do as we all continue to wage our battle against ALS.
November Honored Caregivers

In recognition of the vitally important role of caregivers, we provide special time JUST for caregivers during the month of November. This year is National Caregiver Month. Caregivers are the family and friends on the front lines of ALS and often continue, running the household while caring for loved ones who would otherwise be without crucial support.

From transporting to feeding those living with ALS, caregivers make day-to-day life more manageable and fill it with compassion and loving human contact. This November 2-3, 2014 we held the 5th annual Caregiver Appreciation Weekend at Seven Springs sponsored by Interim Healthcare which provided caregivers a relaxing break to replenish their minds and bodies. It is our way of making sure that those who give the care also care for themselves.

Western Pennsylvania has ONLY ALS Association Certified Treatment Center of Excellence

The ALS Association, along with the Western Pennsylvania Chapter, welcomed the ALS Clinic at Allegheny General Hospital to the Certified Treatment Center of Excellence Program, establishing the clinic as meeting the highest levels of national standards of care in the management of ALS.

On September 6 at the Pittsburgh Walk to Defeat ALS®, clinic director, Dr. Sandeep Rana, was presented with an award recognizing the clinic as an ALS Certified Treatment Center of Excellence.

The Certified Center staff designs, implements and monitors programs based upon national standards of best-practice care in the management of ALS. This distinct designation is only for those institutions that meet the rigorous eligibility criteria, which includes diversity of professional expertise, access to coordinated multidisciplinary care, a strong, ongoing relationship with the local ALS chapter, and active participation in ALS research. This designation ensures that people living with ALS can receive the highest level of quality care and services.

The Western Pennsylvania Chapter has a long history supporting multidisciplinary care by providing grants to fund specialists at The Allegheny Health Network ALS Certified Center of Excellence which is now the only one of its kind in Western PA.

Healthcare Hero: Marie Folino, MSW, LSW

There is nobody more deserving of The Pittsburgh Business Times Healthcare Hero Award than Marie Folino, Director of Care Services. Marie brings an unparalleled sense of devotion and loyalty to her job at The ALS Association Western Pennsylvania Chapter. She is an incredible human being who has dedicated her whole heart and soul to taking care of people with ALS.

Everyone who meets Marie absolutely adores her. Marie is a social worker who advocates for people with ALS and their families. She helps make sure that patients have the specialized equipment needed to aid in speech, mobility and other activities of daily life. She also helps in appealing health insurance decisions that deny coverage for care. In caring for her clients, she says she is reminded of her own father’s illness with Parkinson’s disease and how her family stuck together and helped out with his care to the very end. In addition to getting adaptive equipment to ALS patients, Marie started a program to offer bereavement services to families who’ve lost a loved one to ALS. Marie is also spearheading a program to offer personalized in-home training for ALS caregivers.

“Thanks to the ALS Association’s efficient and effective use of funding from previous budgets for patient care, the Pennsylvania legislature approved the $350,000 line item for ALS patient care in the state budget in 2013, an increase over the previous year. Governor Corbett approved support continuing this essential financial support in his budget proposal for FY 2014-15 and instituted the line item for the next three years! This is a huge win for our Pennsylvania advocates, who work to educate our legislature on the financial needs of ALS patients and their families.

With an understanding of the critical needs for ALS families on a daily basis, and the many budget constraints facing the Commonwealth, the ALS Association is looking to boost the line item funding to $500,000 in 2015. This funding is not only critical to the well-being of all ALS patients in the state, but is also a cost-effective measure that saves the state significant dollars on an annual basis.

This year, outstanding ALS advocate and long time supporter of the ALS Association, Anne Lewis, presented Senator Jay Costa with an award to acknowledge his dedication to the health and wellbeing of our Pennsylvania residents and for being one of the best Senate advocates behind the line item funding for ALS patient care. Jay Costa recognizes the high cost of in-home respite care, wheelchairs, and other medical equipment necessary to maintain quality of life for those living with ALS.

State Advocates Have Great Success in Harrisburg

The Legacy Society was established in 1996 to recognize all those who have generously included the ALS Association Western Pennsylvania Chapter in their long-term financial or philanthropic plans through a bequest, life-income gift or other planned gift arrangement.

Members of The Legacy Society are valued supporters who have determined that their legacy will be one of hope – hope that a cure for ALS will be found and that those living with ALS will have quick and easy access to vital patient services.

MEMBERSHIP

The following kinds of commitments, subject to certain restrictions, qualify for membership in The Legacy Society:

• A bequest provision in your will or revocable trust.
• A life-income gift that names The ALS Association Western PA Chapter as a remainder beneficiary, such as a charitable gift annuity or a charitable remainder trust.
• A charitable lead trust that provides current income to the Chapter.
• A gift or assignment of qualified retirement plan assets, such as an IRA, 401(k), or 403(b).
• A gift of life insurance.
• There is no minimum commitment required for membership in The Legacy Society; nor is proof of a commitment necessary. Members of The Legacy Society may remain anonymous, and all information is kept strictly confidential.

If you have already included us in your will or other planned gift, we hope you will let us know. Your willingness to be listed as a member of The Legacy Society encourages others to follow your example. We acknowledge and respect those who wish to remain anonymous, but urge you to notify us of your plans.

If you have not yet included us in your plans and would like to explore the best options for you and your family, please feel free to contact us. We would be glad to assist you confidentially.

The following are your options:

• A charitable lead trust.
• A gift or assignment of qualified retirement plan assets, such as an IRA, 401(k), or 403(b).
• A life-income gift that names The ALS Association Western PA Chapter as a remainder beneficiary, such as a charitable gift annuity or a charitable remainder trust.
• A charitable lead trust that provides current income to the Chapter.

Our Community
Chapter Events Raise More Than $880,000

This Little Piggy Went to the Market and Brought Home a Record Breaker! Wee Wee Wee!!

2014 is a special year in Johnstown. It is the 125th anniversary of the Johnstown Flood, the 75th anniversary of the Johnstown Walk to Defeat ALS®, and now the 10th anniversary of the Johnstown Walk to Defeat ALS®. and now the 10th anniversary of the Johnstown Walk to Defeat ALS®. The Walk originally started in 2004. Despite record breaking heat, a few hundred people came out to walk. Some of the founding committee members who worked on that Walk still serve on our Walk Committee today: They are Tim Spangler, Frannie Findley, Bobbi Benson, Shirley Mayak, Betty Hostetler, and Jan Goodard. What a devoted bunch! This committee has added some members along the way. Most recently, sisters, Sharon Squillario and Carla Portash took on the roles of Committee Chairmen. Thanks to them, the memorial balloon ceremony was well on its way to success. When the Ice Bucket Challenge was even heard of, the Johnstown Walk was quickly met by our 31 family teams walking in honor or memory of a loved one. The image is made up of the names of every team that participated in the Johnstown Walk for the past 10 years. This is a special thank you to everyone that brought us to such a successful 10th anniversary! A HUGE thanks goes out to Kristi Marsili for creating this unique logo commemorating the Johnstown Walk as team Dozy’s Daffodils and have donated the free lunch provided at the Walk for the past three years. This year he decided to host a kick-off party for the Walk at the family-owned, Wells Creek Station. The kick-off included food, raffles and piggy banks for everyone! The Chapter also received pigs and sent them to Board Members and team captains with one rule...all piggy banks must return to the Walk with full bellies; and they did! On Walk day hundreds of pigs showed up and literally crushed our expectations. We had so many pigs that we could not fit them all on our display board. In fact, the board broke under the weight of the big, fat pigs. The total coinage received from the pigs was more than $1,200.

2014 Johnstown Walk Kick-off party on May 1, 2015 at Wells Creek Station. Join the festivities by contacting Kristi Marsili at kristi@cure4als.org

Scott will be hosting the 2015 Johnstown Walk Kick-off party on May 1, 2015 at Wells Creek Station. Join the festivities by contacting Kristi Marsili at kristi@cure4als.org

For the second year, Merritt Spier presents a $10,000 check to Barb Duryea to support the Johnstown ALS Clinic.

Official Charity of the 2015 Pittsburgh Marathon!

Dr. Tom Fleming, principal at the Bishop McCort High School, challenged his students to raise $500 in a week for ALS. They exceeded that goal and presented a check to us at the Walk.

In Photo:  Jason Jacobetz, Rebecca Renshaw, Brianna Renshaw

In Photo: Gretchen, Jeremiah, Nathaniel Witkowski, Malinda Koncar, Scott Bartholomew, Jamie Bartholomew

One year ago, we were approached by an enthusiastic runner, Rebecca Renshaw, who wished to run in the Pittsburgh Marathon representing the ALS Association in honor of her father. To make this happen we had to go through an extensive application process and prove ourselves as a reputable organization capable of recruiting runners and encourage fundraising. One year later, we are happy to announce that we exceeded our goals and expectations by recruiting 19 runners and raising $12,465! Rebecca is now on our Chapter Board and will be leading the marathon team again this year. Also, on our ALS team is Ms. Pennsylvania, Malinda Koncar. Malinda is a personal trainer at Any Time Fitness and has agreed to work with our runners to develop personalized training plans and diets.

Registration for the Pittsburgh Marathon is now open! This year we hope to double the number of runners and surpass our fundraising total from last year. We are recruiting individuals to run the 5K, Half Marathon-Relay, Half Marathon, and Full Marathon. If you are interested in joining our team, please contact Kristi Marsili at kristi@cure4als.org. If you are interested in donating to our team, go to: https://www.crowdsrc.com/tiealasso-westpachapter.

In Photo: Jason Jacobetz, Rebecca Renshaw, Brianna Renshaw

See page 12 for more information!

Erie Highmark Walk for a Healthy Community- Save the Date!

The 2014 Erie Highmark Walk for a Healthy Community was a blast, as always. We are thrilled to be a part of such a special day. Thanks to our walkers and donors we were able to raise $8,541! We hope to continue to grow this event and spread awareness of our services to the families in need in the Erie area. The 2015 Highmark Walk for a Healthy Community Erie takes place Saturday, June 6, 2015, at Presque Isle State Park. Online registration will be opening soon.

New Event!

Ski to Defeat ALS! Save the Date!

When: Sunday
February 21, 2015
Where: Seven Springs Mountain Resort
Registration starts at 8 a.m.
The 2014 Pittsburgh Walk to Defeat ALS was a success before it even happened. Many months of planning from the Walk Committee, the hard work from the staff and Board of Directors and the immense dedication, and drive from our team captains, patients, donors and sponsors, all came together for our most successful Walk ever. Together, we made history and raised more than $785,000!

Walk season began with our Corporate Recruitment event at Consol Energy Center with Craig and Anne Adams. Their personal presentation inspired the audience to get involved. We can’t thank Craig and Anne enough for sharing their time, not to mention the personal tour of The Penguins Locker Room and an autographed mystery puck raffle! The total for our corporate sponsors this year was $119,107!

Our family and corporate teams worked overtime to raise funds for the Walk. There were lemonade stands, jeans days, picnics, bar crawls, raffles, yard and bake sales, car washes, and then in mid-July the Ice Bucket Challenge arrived. Who would have thought that dumping a bucket of ice water on your head would bring ALS to the world’s attention? The phenomenon took off for our Walk and to the Chapter may never be seen through.

The magnitude of success that the Ice Bucket Challenge arrived in bus loads with 505 walkers and $76,359!

After weeks of hard work, thousands of ice bucket videos, meetings, phone calls, a ton of email and two fundraising goals broken, Walk day arrived on Sept. 6, 2014! Under the bright, hot sun more than 3,200 walkers filled Point State Park and the sight of the 216 different team t-shirts was colorful and amazing. Cheers and laughter filled the air from kids’ crafts, to the ice Bucket Challenge station, to the cotton candy stand to the free therapeutic massages.

None of it would have been possible without our wonderful volunteers, staff and Board of Directors. Thank you to everyone that helped make the 2014 Pittsburgh Walk a huge success. Please join us again next year for our Walk. Judges look for style, creativity, and theme. This is Grover’s Gang’s second year in a row winning the T-shirt contest.
Legacy Sponsor: Hefren-Tillotson, Inc.

In 2011, our beloved coworker and friend, Neil Alexander, received the devastating diagnosis of ALS. The employees and families of Hefren-Tillotson immediately rallied around Neil with support and prayers, and thus began our involvement with the ALS Association of Western Pennsylvania. The passion and dedication of the "HT Stands Up for ALS!" walk team has grown stronger every year since then, driven by the example set by Neil and his family as they deal with this overwhelming disease. Our walk shirts say it all “Hero… Teammate…Friend…Neil Alexander”.

This year, we were thrilled to see the Hefren-Tillotson team continue to grow, with over 125 people of all ages (and even some of our favorite pets) completing the Walk. Point State Park is a fantastic venue for the Walk – easily accessible and plenty of room for the growing amount of walkers. The Point allows people on both sides of the river to witness the magnitude and importance of this event. We were blessed with a gorgeous, sunny morning and warm temperatures. And of course, no view could be more striking than our beautiful city of Pittsburgh.

Neil, Suzanne, Abby and Patrick Alexander have been inspirations for everyone who knows them, finding ways to turn the news of Neil’s disease into opportunities that make positive differences in the lives of many. Through their foundation, Live.Like.Lou.org, and their involvement with the ALS Association, they have raised awareness of the needs of those with ALS in our community. They have also supported families dealing with ALS through several programs and have made grants for critical research.

The ALS walk is one important way for Hefren-Tillotson and Neil’s family and friends to collectively show our support and affection for the Alexander family and to raise money for the ALS Association. The work of the ALS Association is so critical to Neil and so many others as they face a future with ALS. We are so grateful for the support. - Kim Tillotson Fleming

Bereavement Support

The Western PA Chapter has launched a bereavement support group specifically for family members who have survived the death of a loved one to ALS.

Grief is an experience we will all go through at some point in our lives. While grief is a universal experience, it is also a unique experience to each person going through it. There is no right way to manage grief, but there are healthy, more effective ways to cope.

The Chapter has partnered with the Good Grief Center for Bereavement Support, and is offering a series of bereavement support groups that will provide education on how to effectively cope with and better handle the mourning process. For more information please contact the Chapter at (412) 821-3254.

Tribute Gifts

This past year many friends and many new donors to the Chapter chose to celebrate the life of a loved one by making a tribute gift to The ALS Association Western Pennsylvania Chapter. We are happy to designate gifts in honor or in memory of a loved one, or to acknowledge a special occasion or someone who has made a difference in the lives of those living with ALS.

Since our last newsletter (that listed tribute gifts from November 1, 2012 to November 30, 2013) we have received thousands of gifts honoring and memorializing loved ones. We can’t thank you enough for these special donations but as good stewards of the public’s funds and in keeping with our mission to fulfill the critical needs of those we serve, we have decided not to print the list of tribute gifts and names in this newsletter.

When we pulled together the list for printing, it turned out to be over 26 pages of names with each page containing three columns of names in extremely small font. To print it and include everyone (as we would have done) would have cost us an appalling amount of money. Money that could be and will be spent on badly needed patient care and equipment. And this is what we believe our donors would prefer anyway.

Due to the importance of these gifts and the meaning behind them we are making the entire list of tribute names and donors from December 1, 2013 to November 30, 2014 available on our website at the following link: http://goo.gl/Xylrn4. If you do not have access to a computer and would like a paper copy we will print the list and mail it to you upon request. Simply call our office at (412) 821-3254.

Thank you for your support and, in this particular case, your understanding.
Please join us for our 1st Annual Ski to Defeat ALS event and enjoy a fun, family-friendly day on the slopes while raising money that allows our Chapter to sustain ALS care services and support global research. We are pleased to join Three Rivers Adaptive Sports (TRAS) to make this event possible. Utilizing their experience and adaptive equipment, people living with ALS are able to fully participate in the event and enjoy a day on the slopes with their family. We are honored to recognize Matthew Onyshko and family who have previously used TRAS services.

Story behind Ski to Defeat

With the magnitude of success surrounding the signature ALS walks we decided to expand into the winter months. As only the third chapter of the ALS Association to put on a ski event, we hope to attract avid skiers, eager fundraisers and all people living with ALS that would like to enjoy a day on the slopes. Two members of our Chapter traveled across the country to Oregon to observe their chapter’s event and we hope to bring similar success to Western Pennsylvania.

Event Day Details:
• February 1, 2015.
• Seven Springs Mountain Resort.
• Check in at Foggy Goggle 8-10 AM.
• Breakfast served upon registration.
• Slopes open at 9 AM.
• Skiing will run until dinner.
• Reception at 3 PM in the Alpine Room.
• Cash bar.
• Overnight accommodations upon request.

Contact Christy Simmers or Kristi Marsili if interested in participating. (412)282-3254

For more information or to register please visit ski4als.org!

In Photo: Matthew & Jessica Onyshko and family

In Photo: Matthew & Jessica Onyshko with the Deutschtown Fire Department on Ellen

In Photo: Matthew & Jessica Onyshko and family

In Photo: Aricci Marsili, Merritt Spier, Paul Rockar

1st Annual Ski to Defeat ALS - February 1, 2015

Our Local Ski Champions - The Onyshkos

You may recognize this couple from their recent appearance on “The Ellen DeGeneres Show” where Matt and Jess were treated like royalty, surprised by their friends and given a check for $50,000. Matt Onyshko has been a Pittsburgh Firefighter for eight years. He has been living with ALS for seven of those years. Matt and Jess made a choice following the diagnosis to live life to the fullest and have as much fun as possible. They easily admit that they “have nothing to complain about.” Through the kindness of others and Matt’s firefighter brothers, the family has been able to continue to pay for the high cost of care and equipment that comes with ALS.

Matt was an avid skier and he and Jess have volunteered to be our Ski to Defeat ALS Champions for our 1st Annual event. The Onyshkos attended our Ski to Defeat ALS Kick-off party on Saturday, November 15th where guests were treated to their clip from “The Ellen Show.” Matt and Jess received a standing ovation from the crowd and inspired everyone there to help raise money by attending the Ski to Defeat ALS event on February 1, 2015. Since his diagnosis Matt has used the services of TRAS in order to continue to ski.

About TRAS

Three Rivers Adaptive Sports (TRAS) stands by an idea that fits perfectly with the positive attitude expressed by the Onyshkos. “I can do this. I can do anything.” Since TRAS began in 1989 they have supported the belief that sports, recreation and physical fitness are an integral and important part of everyone’s life. Through their specialized equipment, they make it possible for anyone with disabilities to have a safe, enjoyable day on the slopes with family and friends. TRAS is entering their 25th year of providing Adaptive Alpine Skiing opportunities for people with disabilities and are the leaders in the industry. We are pleased to be partnering with TRAS for the First Annual Ski to Defeat ALS event and encourage our PALS to come out and enjoy the day and let TRAS take care of your every need. We promise a safe yet exhilarating day.

In Photo: Matthew & Jessica Onyshko and family

In Photo: Matthew & Jessica Onyshko and family

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Free Throws for Charity

Special thanks to UPMC Center for Rehab Services for donating $10 for every free throw made by the 2014-15 Pitt University basketball team. The team sunk 612 free throws totaling a $6,120 donation from UPMC. Great job, boys. Go Panthers!

In Photo: Aricci Marsili, Merritt Spier, Paul Rockar

Do I know enough about my ALS treatment options?

By Dr. Michael Emanuel, 1976 recipient of the Alfred P. Sloan Award at the age of 38,

I noticed I’m not sleeping as well as I used to and my breathing capacity has declined.

I’m always looking for options that might help me. Should I ask my doctor about the diaphragm pacing treatment?

NeuRx® Diaphragm Pacing System (DPS) provides external electrical stimulation to improve the efficiency of the diaphragm. NeuRx DPS is a non-invasive procedure that is approved by the FDA and has been used in over 400 patients. Eight trial sites and 117 patients have been enrolled in a randomized controlled study to evaluate the efficacy of NeuRx DPS. The study appears to be safe and effective in improving breathing and quality of life. This study is supported by the National Institutes of Health and will be completed in 2014.

NeuRx Diaphragm Pacing System (DPS) is a medical device that is not intended for use in persons with circulatory or respiratory problems. It is not intended for use in patients with cardiac pacemakers or defibrillators. If you have any questions about using NeuRx DPS, please consult your healthcare provider. For more information on NeuRx DPS, please visit www.neurx.com.

Sponsored by Synapsis

Synapsis is a medical device company that provides solutions to improve patient care in the ambulatory setting. Synapsis’ product, NeuRx DPS, is a medical device that can be used to improve breathing and quality of life in patients with ALS. Synapsis is committed to advancing the care of patients with ALS. For more information, please visit www.synapsismedical.com.
Meet the New CEO of ALSA: Barbara Newhouse

If you did not attend the Pittsburgh Walk to Defeat ALS® this summer you missed an appearance from Barbara Newhouse who exchanged the stage at Point State Park that, “the Pittsburgh Walk was the one to beat!” And she was correct. The Walk exceeded all our goals and expectations... but you can see that in the newsletter centerfold.

After an extensive nationwide search for a new CEO, The ALS Association appointed Barbara Newhouse who began work on June 2, 2014. With only one month on the job, the Ice Bucket Challenge hit full force and what an introduction it was! Barb handled it with great professionalism. And, of course she would as she has had an impressive career working for some of the most recognizable nonprofit organizations in the country holding various leadership roles and levels of responsibility.

We were honored to have Barbara visit Pittsburgh and attend our Walk. She looks forward to her next visit and we will welcome her with open arms! You can learn much more about Barbara Newhouse by visiting www.alsa.org.

84 Lumber Makes Single Largest Gift to the Chapter

Thanks to Maggie Hardy Magerko, President and Owner of 84 Lumber and her father Joe A. Hardy, III, founder and CEO of 84 Lumber, The Western PA Chapter of The ALS Association received a check for $122,000 for patient care. It is the single largest donation in the Chapter’s history.

428 associates of the 84 Lumber company participated in the ice bucket challenge. Maggie Hardy donated $250 for each associate and then donated $15,000 of her own dollars to make up the total of $122K. The check was cut on October 31st, and arrived with a letter stating: “The ALS Association Western Pennsylvania Chapter is very near and dear to so many of us whose families have been personally affected by this debilitating disease. ... We are happy to know that 100% of the donation will stay local to Western PA. We are also proud to be a part of helping to make a difference in the lives of those living with ALS: a disease with no treatment or cure.”

THANK YOU 84 Lumber and all of your employees!

Many thanks to our Johnstown Walk Committee: Chairman: Sharron Squillario and Carla Portash

Committee Members:
Shirley Mayak
Trisha Barron
Lisa Jerin
Debbie Larkin
Terri Englehart
Scott Steinkirchner
Susan Bastaja

Many thanks to our Pittsburgh Walk Committee: Chairman: Christi Kolarcik & Colleen Schaefer

Committee Members:
Courtney Zydel
Gina Piel
Rachele Keller
Denise Shipe
Tammy Shields
Nadene Purcell

Thank you to our Corporate Recruitment Committee: Craig and Anne Adams
Neil and Suzanne Alexander
Keith A. Pisarcik

Thank You

• On October 2, 2014 The Association announced an initial contribution of $21.7 million to expedite promising research to find treatments and a cure. Last year a total of $7.6 million was spent on research, so this is an amazing result of the Ice Bucket Challenge and only the beginning.

• Expediting ALS research and drug development remains a top priority and the most significant dollars will be spent in this area.

• People living with ALS and their families come first in everything that we do at the local level. The Western PA Chapter is working to expand and enhance patient care. With the help of Ice Bucket donations, two new programs have been added to our menu of Care Services.

• The ALS Association will be communicating regularly with the community, our donors, the media and the public about progress in funding projects and programs to support the cause. We are proud to have received the highest ratings from Charity Navigator, Charity Watch and GuideStar, which are all well respected nonprofit watchdog groups.

Thank you to our Corporate Recruitment Committee:
Craig and Anne Adams
Neil and Suzanne Alexander
Keith A. Pisarcik

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Ice Bucket Challenge SPENDING:

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• The ALS Association will be communicating regularly with the community, our donors, the media and the public about progress in funding projects and programs to support the cause. We are proud to have received the highest ratings from Charity Navigator, Charity Watch and GuideStar, which are all well respected nonprofit watchdog groups.

Thank you to our Corporate Recruitment Committee:
Craig and Anne Adams
Neil and Suzanne Alexander
Keith A. Pisarcik

Thank You

Ice Bucket Challenge SPENDING:

• On October 2, 2014 The Association announced an initial contribution of $21.7 million to expedite promising research to find treatments and a cure. Last year a total of $7.6 million was spent on research, so this is an amazing result of the Ice Bucket Challenge and only the beginning.

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Thank You
See you soon!

Holiday Party - December 13, 2014
PNC Park - Hall of Fame Club
Ski to Defeat ALS - February 1, 2015
Seven Springs Mount Resort
Johnstown Kick-Off Party - May 1, 2015
Wells Creek Station
Pittsburgh Marathon - May 1-3, 2015
Downtown Pittsburgh
Local Advocacy Day - April 2015
Harrisburg, PA

National Advocacy Meetings - May 10-12, 2015
Washington, DC
Erie Highmark Walk for a Healthy Community - June 6, 2015
Presque Isle Park- Erie, PA
Johnstown
Walk to Defeat ALS® - August 1, 2015
University of Pittsburgh, Johnstown Campus
Pittsburgh
Walk to Defeat ALS® - September 5, 2015
Point State Park