

SPRING/
SUMMER
2013

On WITH **Life** Brain Injury
Rehabilitation
Specialists™

headway

TAKING THE LONG VIEW

FAMILY FROM LOUISIANA FINDS THE
RIGHT FIT IN GLENWOOD

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PEOPLE MAKING A DIFFERENCE | GOLF OUTING | VALENTINE'S DAY PHOTOS

On With Life headway magazine

SPRING/SUMMER 2013

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About the Cover: Zach Jackson and his mom, Dana Johnston, moved from Louisiana to Iowa to receive care in our Long-Term Skilled Care program in Glenwood, Ia. Zach and Dana have quickly become an important part of the On With Life family.



a letter from our director

I'd like to take this opportunity to tell you about an exciting development in the field of brain injury rehabilitation.

For over a decade, the University of Texas Medical Branch - Galveston, and the Transitional Living Center of Galveston have assembled professionals from the United States and Canada to act as a "brain injury think tank." In 2012 and 2013, I was invited to be part of this group focused on the re-conceptualization of brain injury as a chronic condition.

As we have learned at On With Life, traumatic brain injury is often associated with increased risks for a wide range of cognitive, hormonal, physical and emotional changes. Changes may occur at the time of injury or manifest later as a result of degeneration processes triggered by the brain injury. Consequently, brain injury should not be viewed as a sentinel event. Monitoring and addressing these changes over the lifespan can help lessen the many functional, vocational, social and financial difficulties that may occur as a result of the brain injury.

In 2012, we developed protocols to re-conceptualize brain injury across the domains of public policy, education, medical practice, research and psycho-social interventions. In 2013, we focused on brain injury over the life span: bridging the gap and treating brain injury as a chronic disease. We targeted five essential components to help make this a reality: delivery system design guidelines, practice changes, medical, self-support, and community integration.

It was a tremendous honor to be invited to these gatherings. I am proud to say that On With Life's experience in helping people not just survive, but thrive after brain injury was represented in this effort!


You can find the articles summarizing each 2012 workgroup conclusion in Volume 10, Issue 1 of the "Brain Injury/Professional" publication of the North American Brain Injury Society.

Julie Fidler Dixon, *Executive Director*

P.S. If you've received Headway previously, you may notice our updated look. On With Life recently decided it was time to make some updates to our materials, including our new website (www.onwithlife.org), informational brochures and publications like Headway. We hope you enjoy our new look – we sure do!

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Kay Sterbick, RN, On With Life quality care coordinator, is pictured with Bonnie, person served in our Post-Acute Inpatient Rehabilitation program. The On With Life Quality Care Coordinators are an essential part of the rehabilitation we provide. Our care coordinators work hand-in-hand with the person served and their family to coordinate healthcare, including communication with the interdisciplinary team, nursing staff and On With Life physicians.

ON WITH LIFE HONORED AS A FINALIST FOR THE Des Moines Register's Aurora Award

The Aurora Award recognizes nonprofit organizations that have identified a need in the community and have worked to fill that need. As stated by Kurt Allen, the Des Moines Register's chief marketing and strategy officer, "The Aurora Awards link The Des Moines Register's vision of building a better quality of life in Iowa with individuals and organizations that are honoring that vision."

"While each day continues to be a challenge in its own way, with a lot of hard work and the excellent rehabilitation provided by On With Life, my family and I have been able to get on with life," wrote Heather DeJooode in her nomination letter for On With Life.

Congratulations to the 2012 Aurora Award Winner, Central Iowa Shelter & Services, an organization that provides free shelter and meals to homeless adults, and the 2012 Iowa Star Winners, Des Moines Philanthropists, Susan and Bill Knapp.



The Des Moines Register

On With Life was named a Des Moines Register's Top Work Place of 2012 after a comprehensive analysis conducted by Workplace Dynamics. The results are a direct result of the mission of On With Life and the importance we play in the lives of persons served and families.

"We feel like we are the most privileged people in the world," said Julie Fidler Dixon, executive director at On With Life. "Every employee gets the chance - whether they are a nurse, CNA, therapist, or support person - to truly make a difference in someone's life."

CARF Accreditation

CARF International announced that On With Life, Inc. has been accredited for a period of three years for its brain injury programs, stating that "On With Life provides a unique and critical resource to this region of the country – the program puts significant resources into staying current in the field of brain injury and ensuring that staff has access to ongoing evidence-based learning opportunities." This is the seventh consecutive Three-Year Accreditation that the international accrediting body has awarded to the On With Life continuum of services, including:

- Comprehensive Integrated Inpatient Rehabilitation Program – Skilled Nursing: Brain Injury (Adults; Children and Adolescents)
- Interdisciplinary Outpatient Medical Rehabilitation Programs: Brain Injury (Adults; Children and Adolescents)
- Independent Evaluation Services (Adults; Children and Adolescents)*
- Home and Community Services: Brain Injury Program (Adults)

This accreditation decision represents the highest level of accreditation that can be awarded to an organization and shows the organization's substantial conformance to the CARF standards.

* On with Life is CARF's first program ever to be accredited in this category.





At On With Life we take great pride in our **Valentine's Day Sweetheart Dinner** hosted for persons served in our Post-Acute Inpatient Rehabilitation program. On February 14, staff and volunteers transformed one of our therapy gyms into a beautiful setting complete with great food, flowers, music and friends. It was a wonderful night for all involved.



taking
the

long view

Family from Louisiana finds the right fit in Glenwood

In the early morning hours of April 17, 2009, Zach Jackson was in an SUV roll-over accident, hit a tree and suffered a traumatic brain injury. And as is so often the case with an anoxic brain injury – which means Zach’s brain was deprived of oxygen for an extended period of time – it was difficult to determine in the hours, days and weeks after the accident what recovery would look like for the 18-year-old.

Further complicating things was the fact that Zach had also experienced brain stem damage.

His mother, Dana Johnston, remained Zach’s biggest advocate as he moved from the trauma unit of Louisiana State University Hospital to an acute care hospital in Shreveport, La. That stop was just the beginning of a winding journey that led Zach to On With Life’s Long-Term Skilled Care Program for Youth and Younger Adults in Glenwood, Iowa.

After seeing Zach make small strides forward and then plateau after receiving care at facilities in Houston, New Orleans, Mesa, Ariz., and Bossier, La., Dana began looking for something more. Internet searches for offerings that served young adults with traumatic brain injury turned up some results, but Dana said none of them felt “right.”

“I spent many mornings, evenings and free time looking for a place Zach could live long-term,” Dana says. While Zach has made progress in the years since the accident, he still cannot walk, talk or feed himself. “The nursing home setting was not for him at all. And some of the places I came across online wouldn’t take him because he couldn’t use his hands, or because he had a feeding tube, or because he wasn’t independent enough.”



Dana and Zach are huge New Orleans Saints fans and had the opportunity to meet Drew Brees in 2010 after their Super Bowl win.

But Dana knew that something needed to be done. In the nursing home in Bossier, Zach was down to just 96 pounds and she could see in his face that he wasn't happy.

"I went home [from seeing Zach] crying most days," she recalls. "I finally decided we needed to do something."

With the encouragement of her husband, Dwaine, Dana reached out to On With Life and connected with social worker Julie Wells. The two hit it off right away and Dana decided to come to Iowa for a visit.

"As soon as I got there, I knew it was where Zach needed to be," Dana says. "And Julie and the rest of the staff at On With Life did all they could to get us there."

"It was in February or March of 2012 that Dana connected with me and we began to email back and forth," Julie recalls. "Moms and dads of children who have a brain injury will do whatever it takes to get them the care they need. Dana was determined to find the right fit for Zach and we were happy that she chose to bring him to On With Life."

Zach moved in on December 31, 2012.

"We started the New Year with a bang," Dana says with a chuckle. Dana followed Zach to Iowa and lives in Glenwood. She says she knew early on that they had made the right decision in coming to On With Life.

"It's not the huge things I'm looking for," Dana says. "What I've been impressed with is the fact that they are not going to give up on Zach and they are not going to let him give up on himself. He is respected, he has his dignity back and he is happier. Those are the things I'm looking for."

While Zach works with a variety of care providers, he has grown close to his physical therapy assistant Jan Hustak. Dana says Zach's connection with Jan has gone a long way in terms of improving his mood and demeanor – even if they didn't hit it off right away.

"I could tell at first he wasn't real sure about anyone, including Jan," Dana says. "But about a month after we were here, I was sitting with Zach alone and I asked him, 'Do you like it here?' and he lifted his foot to tell me 'yes.' I then asked him if he felt like he was being treated better here and again he answered that he was."

"That made me feel really good. He has put his complete trust in them and so have I."

Jan says the team is taking the long view with Zach.

"We know we are probably not going to see overnight success, but that's not going to stop us," she says. "We are all about the long-term. We will continue to work and continue to progress, even if it's just one small step at a time."

The therapy team regularly works with Zach on his flexibility, provides therapy in the pool and is using a technique designed to stretch his muscle fibers and break down scar tissue. Jan says she has been impressed with Zach's commitment.

"When he first moved in, he didn't want anything to do with therapy," Jan says. "But as we've helped him build trust in us he has shown a real willingness to work in therapy. His acceptance and participation has been the key to the gains we have seen."

Among those "gains" are more than 10 pounds. A sign, Dana says, that Zach is comfortable in his new surroundings.

"More and more of his personality is coming about each day," she says. "He has just made so many friends here, especially among the nursing assistants. But they're not the only ones. Everyone here – from administration down – is out and about. They are visiting with families, visiting with persons served. It's one big family here."

And Julie says that family wouldn't be the same without Zach... or Dana.

"Dana's spirit, advocacy and faith are unmatched," Julie says. "That is an asset to us. She knows nothing is guaranteed, but she remains faithful and prayerful. That is an inspiration to all of us."

Learn more about our Long-Term Program at

onwithlife.org

Zach and his sister Kim at a wedding prior to his 2009 accident.





ACHIEVEMENTS

through inspiration

KATE'S JOURNEY

Everything changed for Kate on March 9, 2012 when she was found on the floor by her 15-year-old son, Daneel, unable to speak or move the right side of her body.

There is no doubt that sustaining a brain injury is a life-changing event for everyone involved. It changes families, professional lives, perspectives and attitudes. Living with a brain injury can be especially hard for someone who strongly identifies with and defines themselves through their accomplishments and abilities.

Enter Ekaterina (Kate) Belashova, a smart, strong-willed woman who came to the United States when she was 27 years old. Kate was committed to making a difference and looked for every opportunity to learn. After already receiving a Master of Arts in History in her native country of Ukraine, Kate decided to continue her education and in 2004 graduated from Drake University with an MBA and a 4.0

grade point average. She also completed an organic chemistry class at the local college when she thought the information would be helpful in her career; and although she was already fluent in three languages, Kate also began taking Spanish language classes. An achiever by any standard, Kate was dedicated to meeting her goals.

Everything changed for Kate on March 9, 2012, when she was found on the floor by her 15-year-old son, Daneel, unable to speak or move the right side of her body. Kate was taken to Mercy Medical Center in Des Moines where a CT scan confirmed that she had suffered a stroke on the left side of her brain. Kate was admitted to the hospital's acute rehabilitation unit for her initial rehabilitation

and started On With Life's Outpatient Neuro Rehabilitation Program on April 2, 2012.

"When Kate started therapy with us, she was ambulating well, but her right arm was largely non-functional," explained Courtney Huber, speech pathologist at On With Life. "Kate also suffered from severe aphasia, a condition that robs you of the ability to communicate. She was only able to communicate verbally with answering yes or no questions."

For the next few months Kate worked extremely hard in therapy to gain back as much as she could, explaining in an interview that therapy is an extremely frustrating process, but she tries to stay positive.

"I'm very determined to meet my goals," Kate explains through a combination of writing out her answers and communicating in short affirmative responses. "It is a hard thing to know what you want to say, but not having the ability to communicate it effectively."

Kate continues to visit On With Life on an outpatient basis to receive speech therapy, but is more well known within our walls for a different role. Since February 19, 2013, Kate has served as a volunteer in our Inpatient Rehabilitation Program, attending Wellness Group multiple times per week and helping any way she can.

"Kate has such a kind demeanor and our persons served feel almost instantly comfortable around her," said Amy Bishop, music therapist at On With Life. "I introduced her to a former person served recently who also has severe aphasia and there was an immediate bond between the two. It is an amazing thing to be able to connect with someone on that level and Kate has that ability."

Volunteering has proven to be more than just a one-sided benefit.

"Not only is Kate able to be a part of a persons served recovery as someone who is there to support them, she can also benefit herself from being in that treatment session to challenge her own communication skills," said Bishop.

Kate has been an inspiration to many and even through a tremendous amount of adversity over the last year, she continues to remain optimistic.

"Kate has been the model of persistence, as well as a stark reminder that internal motivation is only one piece of the puzzle when it comes to recovery from a brain injury," explained Huber, who continues to work with Kate on her speech and communication goals. "She has worked her tail off in all of her therapies and outside of her therapies and she continues to make gains every day."

It is clear, however, after even just a short time with Kate, that she isn't yet satisfied with her level of recovery.

"I've made good progress, but I want to make even more," explains Kate. "I'm very determined and dedicated to meeting my goals."

If history is any indication, Kate won't be giving up anytime soon.



Since February 19, 2013, Kate has served as a volunteer in our Inpatient Rehabilitation Program, attending Wellness Group multiple times per week and helping any way she can.

Learn more about our Outpatient Program or becoming a volunteer at onwithlife.org

GET TO KNOW

David Demarest, Ph.D.
Neuropsychologist
On With Life



David Demarest, Ph.D.



Experience:

30 years as an Iowa and Nebraska licensed psychologist.

Fellowship:

University of Missouri - Columbia

Doctorate Degree:

West Virginia University, Morgantown, West Virginia

Clinical Internship:

University of Oklahoma Health Sciences Center/ Veteran's Administration Medical Center

Undergraduate Degree:

University of Virginia, Charlottesville, Virginia

Interesting Facts:

- Dr. Demarest's father was in the military and they moved to Germany when he was three. His early years in Europe inspired a love of languages and an appreciation of different cultures.
- His 22 year old son is in the United States Marine Corps.
- He used to play for a competitive soccer league in Des Moines.

Earlier this spring we sat down with Dr. Demarest, neuropsychologist at On With Life, to discuss recent trends in the field of brain injury.

Q: Can you tell us about stem cell research and how it might affect therapy for brain injury?

A: The use of stem cells to repair or replace damaged brain tissue is a new and exciting avenue of research. A stem cell is essentially a "blank" cell, capable of becoming another specific kind of cell in the body. In the field of brain injury, recent advances continue to lead us to consider that, in the future, stem cells will be able to be used to treat damage to the brain's and spinal cord's nerve cell damage. A neural stem cell – a self-renewing stem cell from the central nervous system, is a special kind of cell that can multiply and give rise to other more specialized cell types. Stem cells represent a potential, new important method of treatment for those who suffered brain injuries and stroke. Ongoing research indicates that stem cells have great potential and promise to repair neural pathways, therefore healing a damaged brain and enhancing recovery of neural function.

Q: It's been reported strokes are happening to people earlier in their lifetime, than in previous years. What steps can we take to prevent this?

A: Up to 80 percent of all strokes can be prevented. One of the ways people can prevent their risk of getting a stroke is by watching their blood pressure and cholesterol levels. High blood pressure and cholesterol can clog arteries and is a major stroke risk factor if left untreated. People can also manage their exercise and diet. Maintaining a diet low in calories, salt,

saturated and trans fat and cholesterol paired with daily exercise, will lessen the strain on the circulatory system. They should also consider identifying atrial fibrillation (Afib) which is an abnormal heartbeat that can increase stroke risk by 500%, stop smoking, control diabetes, and treat circulation problems.

Q: Recent trends are arguing that brain injury can be thought of as a disease/life-long issue. Do you support this idea?

A: There is more and more research that supports this idea and I would agree with that information. People who experience a brain injury, even a mild one, have a 3-fold increased risk of dying prematurely for any cause for at least 13 years after the injury, regardless of the severity of the injury. Traumatic brain injuries, whether mild, moderate, or severe, have been linked to a doubling of dementia risk (Alzheimer's Association International Conference, 2011). For instance, some NFL players are showing major dementia as early as their mid-50's.

Q: What trends should we be aware of in brain injury recovery?

A: Doctors are increasingly doing more of what's referred to as "brain bypass surgery." Like in cardiac bypass, it uses other blood vessels to circumvent and go around problem areas in the brain. In a study at Krembil Neuroscience Center at Toronto Western Hospital, the improvement was notable and quite uniform. Everybody who had a successful bypass had a restoration of thickness of their cortex back to normal, which was really striking and unexpected.



out & about

Many people don't think about bowling alleys, fishing trips and classic cars when they think about the word therapy, but at On With Life we do. Our therapy staff and persons served enjoy outings all year long and we see it as an important part of the rehabilitation process.





people making a

DIFFERENCE



“There’s something about being the first contact with families and representing On With Life that I really enjoy.”

Judy Hilt, RN, BA, CRRN, CBIS

Rehabilitation Nursing Consultant

Twenty-one years ago, On With Life offered a job to Judy Hilt and from that day on, she has been an invaluable asset and brain injury rehabilitation expert for the organization.

Judy began her career in the brain injury rehabilitation in 1977, working as a clinical manager for a rehabilitation facility in Waterloo, Iowa. In August 1991, just two weeks prior to the opening of On With Life, Judy began her career as Director of Nursing.

Judy was first charged with hiring and developing the nursing staff. Her initial guidance is one reason the On With Life nursing staff continues to be the best in the field today. In 1993, Judy was influential in the development of our Disorders of Consciousness program which addresses the rehabilitation needs of persons served in a coma. To this day, On With Life is one of only a few rehabilitation programs offering services to this population in the Midwest.

During her time at On With Life, Judy has worn many hats, including nurse evaluator, life care planner, case manager and director of marketing. These roles allowed Judy to establish and maintain personal relationships with many hospitals, case managers, social workers, nurses and doctors throughout the Midwest. She has been instrumental in developing a trusted reputation and name for On With Life.

While Judy retired from her full-time position in December 2012, she continues to be a valuable contributor to On With Life as a part-time nurse evaluator.

“I have always loved the on-site evaluations,” said Judy. “There’s something about being the first contact with families and representing On With Life that I really enjoy.”

People like Judy are what keep the On With Life reputation so strong. Her dedication and commitment is truly inspiring.

Janet Phipps Burkhead

Board Member

On With Life, Inc is excited to announce the appointment of Janet Phipps Burkhead to its Board of Directors. Janet is an attorney and has just retired as a Brigadier General from the Iowa Army National Guard after 28 years of service to our country. Janet's professional experience also includes serving as Director of the Iowa Department of General Services and the Michigan Department of Management and Budget.

Q: Can you describe what you do professionally on a day-to-day basis?

A: I specialize in intellectual property law assisting clients in protecting their intellectual property assets such as trademarks, copyrights, and trade secrets.

Q: What does it mean to you to be on the On With Life Board of Directors?

A: It means bringing whatever expertise

and experience I have to the Board to support the mission of On With Life not only with an internal focus as to the programs and services offered, but also to those in the greater community to heighten the awareness of this wonderful facility.

Q: What initially made you decide to become a board member?

A: I toured On With Life a few years ago for a Rotary fellowship meeting and was tremendously impressed by the staff and facility regarding the extent of the services provided and the caring, professional manner in which these services were provided. Coincidentally, I began my career as a registered dietitian at Woodward State Hospital School, a sister campus to Glenwood which now hosts an On With Life program.



"I'm looking forward to working with other Board members to support On With Life's mission and to ensure it remains a leader in brain injury rehabilitation."

Laura Martin

Supported Community Living Specialist

On With Life's Supported Community Living (SCL) program was created in 1998 to allow those who have experienced a brain injury or other neurological impairment to maintain and improve their independence. Staff at SCL work together with persons served, families and case managers to develop a plan focused on maximizing personal skills. Services are provided in Polk, Warren, Jasper, Story, Dallas, Marion and other Central Iowa counties.

A major contributor to the program's success, Laura Martin, has enjoyed the uniqueness of the job in her 11 years as an SCL specialist.

"I love the variety. I can wake up in the morning knowing that every day is different," said Laura. "Having the chance to share that feeling of accomplishment

with the persons served, and see their appreciation, is one of the most rewarding parts of my career."

Laura works closely with our persons served to help them find independence and build relationships in the community. A day might include relearning household chores, budgeting, cooking, and setting goals and appointments. SCL specialists work with persons served to attend community outings including I-Cubs games, the Annual Reunion, Adventureland, and the State Fair.

When Laura is not working she enjoys spending time with her children, a 10-year-old daughter and 12-year-old son, biking, and scrapbooking.



"Having the chance to share that feeling of accomplishment with the persons served, and see their appreciation, is one of the most rewarding parts of my career."

7th Annual On With Life Golf Outing & Silent Auction

On With Life hosts its 7th Annual Golf Outing and Silent Auction on Thursday, August 1 at Otter Creek Golf Course in Ankeny. Enjoy lunch and an afternoon of golf, followed by a silent auction and dinner. The outing is an annual fundraising event for On With Life with proceeds benefiting persons served.

Past proceeds have allowed for the purchases of specialized equipment to improve the lives of persons served, including a Visi-Pitch to improve speech, Tilt 'n Space wheelchairs, a mini-bus used to transport persons served, and a SaeboFlex System to maximize arm and hand function.

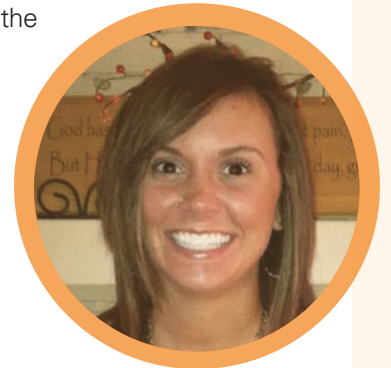
Online Auction

Are you unable to attend this year's event but would still like to support On With Life? You're invited to place an online silent auction bid prior to the golf outing. A representative will be on hand the day of the event to place bids for you, up to the maximum amount provided.

Honorary Co-Chairs

Lizz Cassler's first-hand experience with On With Life led her and her mother, Barb,

to serve as Honorary Co-Chairs for this year's event. In December 2008, Lizz was traveling with friends after school when the car hit a patch of "black ice," and hit an oncoming truck. After four weeks in the hospital, Lizz was admitted to On With Life where staff helped her relearn daily life activities such as eating, drinking, standing and walking.



"Our family has experienced the benefits of On With Life and we are happy to support an organization that truly helps families when they need it most," said Lizz. "Not only did On With Life help me, they helped my entire family. I wouldn't be where I am today without them."

Learn more about the event, including registration, sponsorship details and the online silent auction, by visiting www.onwithlife.org.

On With Life Announces Launch of New Website

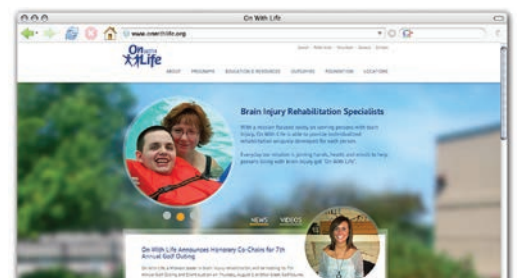
On With Life is excited to announce the launch of our new website, a source of information for persons served, families, the medical community, supporters and all of our stakeholders interested in learning more about the unique care we provide.

The redesigned site, created by Blue Compass Interactive based in West Des Moines, highlights the uniqueness of the services provided at On With Life and showcases our knowledge in brain injury rehabilitation.

The new site offers many new and updated features:

- A news section highlighting what is happening at On With Life and within brain injury rehabilitation.
- Location pages highlighting the communities we call home.
- Video content showcasing staff and the continued progress persons served show each day.
- Valuable information for persons served, families and healthcare providers related to treatment options and equipment.
- Testimonials from former persons served and their families.
- How to connect with us on social media.

Learn more by visiting our new web site at www.onwithlife.org.





wellness fair

To celebrate Brain Injury Awareness Month in March, our Post-Acute Inpatient Rehabilitation program held its annual Wellness Fair on March 3. Persons served were able to select a specific area of brain injury education, research that topic, and put together a presentation on what they wanted to share with staff and other persons served. Topics included Parenting Post-Stroke, Rights and Treatment of Person's Served with Brain Injuries, Life after On With Life, Aphasia, and Emotional and Mental Side Effects to a Brain Injury.





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Joining hands, hearts, and minds to help persons living with brain injury get **On With Life**.

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2013

FFA Enrichment Center
Next to the DMACC Campus
Ankeny, Iowa
Hickory Park
Catering

KEYNOTE SPEAKER :
Susan Voss, Former Iowa
Insurance Commissioner

Top 10 Things Healthcare Reform Will Mean to the Brain Injury Field

Intended for healthcare providers, the On With Life Fall Conference brings together experts from around the Midwest to discuss recent trends in the field of brain injury. Topics will include adaptive and mobile technology, lymphedema management, Mandt behavioral training, caregivers depression, components of a disorders of consciousness program and implications of healthcare reform.

COST:

\$50 (no CEU credit)
\$60 (with CEU credit)

**FOR MORE INFORMATION
AND TO REGISTER, VISIT:**

www.onwithlife.org