



Why We're Here
Personal stories from
our friends & families

Highlights

Coming Up

Join us for SBAIL's
fall events

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Profiles

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of TravelinWheels

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In the News

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about Spina Bifida

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For more information on anything seen in this edition of *Crossroads*,
please contact the SBAIL office at:

(773) 444-0305

or

sbail@sbail.org

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Message from the Board President, Mark Bernstein

It is hard to believe that the summer of 2011 is nearing an end. It is now that time of year when thoughts turn from summer vacations, camp, the beach or the pool, to the beginning of a new school year, or the start of a new job. For most, it is a time of mixed feelings — regret that summer is coming to an end, but excitement for what the future holds.

This year, however, the end of summer is different for us all. The partisan bickering and posturing by our elected officials has caused serious consequences. Regardless of your means, it appears that the difficult economic environment will continue. The tough times will hit the needy and disabled particularly hard, as they always do.

It will be left to organizations like SBAIL to step up and help where other institutions that usually provide support cannot or will not provide assistance to the less fortunate. That is why we all need to learn from, not copy, how our elected government representatives have acted. We will not be able to make things better if we act like they have. We need to work together, to be open minded, and to be willing to have a civil and thoughtful discussion about our priorities.

Rather than viewing the current situation with despair, however, we at SBAIL view it as an opportunity and a challenge.

At SBAIL, we recognize that we all benefit when those who are less fortunate can be productive members of society. Our focus and goal has therefore been and continues to be improving the lives of those affected by Spina Bifida.

This year, in spite of the economic hardships, we've continued to begin new programs designed to help improve the lives of those affected by Spina Bifida, most notably our unique and far-reaching projects, [The Greening of Anixter Village](#) and [Play Date](#). These programs are designed to have effects that are further-reaching than even the most resilient recession.

If we work together, we can continue to rise above the current state of affairs and provide the assistance that will help those with Spina Bifida overcome the daily obstacles that are part of their condition to become independent and self sufficient. By working with you, we can meet the current challenges.

Whether you choose to help by donating your time or money, by writing elected officials to advance our cause, or by simply participating in our programs or events, we need all of the support you can give.

We thank you for your continued support — if we do not help ourselves, no one else will. We look forward to your input and participation during the coming year.

Best of luck,





Letter from the Executive Director, Amy Maggio



This summer has been a challenging time for all of us. Between the excessive heat warnings and the terrible storms leaving us with flooded basements, electrical outages, downed trees, and short tempers, it has been hard to keep our heads above water as we try to balance these damaging storms with work, family and friends, and our daily responsibilities. We've all taken a hit this summer. For some, it came in the form of spending an entire Saturday moving water (and their possessions) out of their homes instead of relaxing as planned. For others, it was the loss of a day's pay because their office was out of power.

But I know that, in the midst of these aggravations, I often forget that it is during these truly trivial struggles that I should be most grateful that I have a home to flood, a job to miss, and the ability to clean out my basement independently. So many people in our society lack one, two, or all three of these luxuries. Unfortunately, a great deal of people with Spina Bifida are among this group.

SBAIL is working hard to make these luxuries more accessible to people with Spina Bifida.

One way SBAIL does this is by continually expanding our programming at Anixter Village, a unique, accessible, and affordable apartment complex dedicated to aiding young adults with Spina Bifida in their transition to independent adulthood. Just this spring, SBAIL and our partners, the [Kiwanis Clubs of Illinois-Eastern Iowa](#), began a ground-breaking project called "[The Greening of Anixter Village](#)." It is a fully-accessible, "enabled" garden (which will soon offer its own farmers market) aimed to help [Anixter Village residents](#) manage responsibilities, improve their nutrition and living space, and acquire valuable vocational skills.

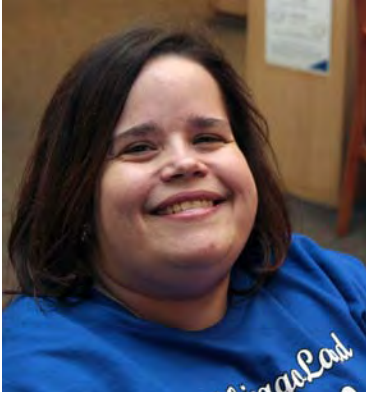
This spring, we also began a new program for children with Spina Bifida under age six called "[Play Date](#)." The group meets monthly at [Shriners Hospital for Children, Chicago](#). While kids play on a safe and accessible indoor playground, parents can share information and discuss their shared experiences. We hope that this program will enable parents and children to establish a lifelong community with others encountering similar issues.

Both of these new programs as well as our existing programs like our [support groups](#), [scholarships](#), [family outreach](#), and [emergency assistance](#) are steps in the right direction to help those affected by Spina Bifida achieve their long-term goals and to lessen their significant struggles.

Here in the office, we are busy planning for our fall events, the [Swing for Spina Bifida](#) golf outing, the [Fall Family Classic](#) picnic and walk-and-roll, and the [14th Annual Memorial Walk-and-Roll-A-Thon](#). Each of these events promises to be fun and exciting. Please consider participating in any or all of these events as your support will enable us to continue implementing and developing these essential programs.

Wishing you all the best and hoping to see you in September!

A handwritten signature in blue ink that reads "Amy H. Maggio".



Update from Anixter Village

By Carolee Stanmar

Greetings from Anixter Village!

I hope everyone has been taking advantage of the summer despite the very wet July.

Anixter Village has been very busy this summer. With the help of the Spina Bifida Association of Illinois, the [Kiwanis Clubs of Illinois-Eastern Iowa](#), and several other organizations, Anixter Village has started an [enabled garden in our backyard](#). In a year or two, once our plants are older and the growth of our crops picks up, we are hoping to turn the garden into a farmers market.

The goal of the garden is to teach the tenants at Anixter Village about gardening and, once the farmers market opens, about the experience of running their own business. These experiences will (and already has) help us gain a sense of self-sufficiency and independence that we can use in the community. Working with different organizations has also enabled us to educate people about Spina Bifida who might not otherwise know about it.

To read more about the goings-on at Anixter Village, please see page 12.

It's the beginning of August and the garden is already blooming with several different herbs, vegetables and flowers. We've already been able to harvest lettuce, green beans, chamomile, and cucumbers. We are still waiting for the popcorn (Yes, popcorn!) and the tomatoes to be ready. The weather has been so unpredictable that the tomatoes just don't know what to do with themselves!

As one of the gardeners, it has been an amazing experience to watch the garden grow. Every time I go into the garden I can't believe that it all started out as just seeds. I love going into the garden and seeing things grow that I know I had a hand in. Being able to go into the garden and pluck fresh vegetables off of the vines that I know we grew ourselves is also an amazing feeling — and makes for an amazing snack! There is nothing better than a fresh red pepper right out of the garden.

I hope your summer has been as fruitful as ours!

Carolee Stanmar



Stay Up to the Minute with SBAIL!

Like us on [Facebook](#) or follow us on [Twitter](#) for instant updates on SBAIL activities, events, and news. On these sites, we regularly publish news stories related to Spina Bifida, offer updates on our programs and events, and share information from our friends that might benefit our followers. Don't fall out of the loop — start following us on social media outlets today!



Introducing Matt Larsen

SBAIL's New Development Manager

Article by Carolee Stanmar

If you've called the Spina Bifida Association of Illinois (SBAIL) office in recent months, you've probably heard a new voice on the other end. That voice belongs to Matt Larsen, SBAIL's new Development Manager. Matt manages individual giving, events, office operations and helps develop plans for SBAIL's social media and marketing. But there's more to Matt than just a job description—and it is all of these other characteristics that make Matt such an important asset to SBAIL.



While Matt did not previously have any personal connection to Spina Bifida, his previous experiences enabled him to understand the challenges — and joys — that disabilities can present to a family. Matt has a relative and several close family friends with disabilities who have made a strong impact on him. “They and their immediate families are really my heroes because of their strength of character. While I'm new to the world of Spina Bifida, I quickly saw the same strength and commitment in the SBAIL community.”

If you have any questions, want to make a donation, or want to register for an event, Matt is now your go-to guy!

When a job for a development manager opened at SBAIL, Matt saw an opportunity to get involved with an organization that helps people lead healthy, fulfilling lives. The more he learned about SBAIL, the more he wanted to get involved.

“I was looking to join a mission-driven organization with strong roots in the community. SBAIL's forty-year history, legacy of grassroots leadership, and state-wide scope made SBAIL an ideal fit for me professionally. Personally, though, I was impressed by the community of people affected by Spina Bifida and the professional community that serves them. I'm amazed by the advances in medical treatment for people with Spina

Bifida. It's an ideal situation when your professional interests and personal values can meet in one job and that's what I've found here.”

The circumstance hasn't only been great for Matt, though. Because Matt is so invested in helping provide programming like the [Greening of Anixter Village](#) and [Play Date](#) to the SBAIL community, SBAIL has already benefitted from his involvement with the Association.

SBAIL is thrilled to have the focused and driven efforts of Matt on board! ❖

Fundraise Online with SBAIL!



In the age of the Internet, fundraising couldn't be easier. The days of walking door-to-door for pledges and making phone calls to close friends and family are over. Now you can fundraise online anytime! SBAIL is proud to introduce its new **FirstGiving** page, firstgiving.com/SBAIL. On our FirstGiving site, you can set up a personal fundraising page for an **upcoming event** or just because!





Swing for Spina Bifida

Stonewall Orchard Golf Club — [map](#)
Thursday, September 15, 2011
12:00pm to 8:00pm



This year, [Swing for Spina Bifida](#) will again be hosted at [Stonewall Orchard Golf Club](#) in Grayslake, Illinois. Stonewall Orchard Golf Club’s course was designed by Arthur Hills, one of the world’s top golf course designers, and was the host of the 2010 Illinois PGA Section Championship.

Registration includes a full round of golf and golf cart rental, lunch, dinner, beverages, and participation in the evening’s raffles and silent auctions.



Memorial Walk-and-Roll-A-Thon

Constitution Trail at Tipton Park — [map](#)
Sunday, September 25, 2011
Registration at 11:30am. Walk at noon.

The 14th [Annual Memorial Walk-and-Roll-A-Thon](#) will be on Sunday, September 25th in Bloomington, Illinois. Come join SBAIL for a walk-and-roll and picnic in the park that will honor the lives of Emma Kenny, Shannon Kolodzieski, Kaylin Rood and Sarah Whitted.

Event registrants will receive a free tee-shirt and picnic lunch and are encouraged to raise pledges. Those raising over \$500 in pledges will win great prizes, so [register and begin fundraising](#) today!

Fall Family Classic

The Center in Palos Park — [map](#)
Sunday, September 25, 2011
Registration at 11am. Walk at 11:30am.



The [Fall Family Classic](#) is coming up on Sunday, September 25th. Join SBAIL for a walk and picnic in the park. Event participants will enjoy a day of family fun with face painting, a petting zoo, hay rides, and much more!

[Registration](#) is \$25 per individual or \$50 per family. Those who wish to participate are invited to [raise pledges](#). Individuals raising \$25 or more in pledges and families raising \$50 or more in pledges will participate for free.

Individuals raising over \$500 will be awarded with a digital camera or a portable GPS navigator.

Event Registration

To register for any of these events, please visit www.sbail.org or email [Matt Larsen](mailto:mlarsen@sbail.org) at mlarsen@sbail.org. You can also call the office at (773) 444-0305 for help registering offline.



Volunteers Needed!

SBAIL could use your help as a volunteer in a variety of ways. Most of our volunteer opportunities are in-office and anyone who feels they can help SBAIL is welcome to contact [Matt Larsen](mailto:mlarsen@sbail.org) at mlarsen@sbail.org or by phone at (773) 444-0305.

Aside from general office help, we offer [volunteer opportunities](#) in the fields of public relations, marketing, IT, fundraising, and event planning. We also welcome volunteers who wish to help with day-of-event activities at any of our upcoming events.

Donate Now!

The Spina Bifida Association of Illinois relies on public donations to continue its work. Your support of SBAIL ensures that it is able to continue to pioneer programs that help meet the needs of more than 4,000 people throughout Illinois and northwest Indiana. To make a donation, please visit www.sbail.org or call the SBAIL office at (773) 444-0305 for help donating by mail.

spina bifida in the **news**



state

A very deserving six-year-old with Spina Bifida and her mother were recently surprised by ABC7 Chicago with two tickets to see Paul McCartney perform live at Wrigley Field.

Camera crews were waiting to capture their reaction. Footage of the surprise is available online at [YouTube](#) and [ABC7.com](#).

<http://www.youtube.com/watch?v=UgYbBxN3fj8>



nation

In May, a Dallas couple went to a Houston hospital so doctors could perform the first fetal surgery to repair Spina Bifida-related defects to their unborn daughter.

The baby, Faith, was born on July 4th. Faith is doing well and this type of surgery sounds like a promising option for future babies with Spina Bifida.

<http://abclocal.go.com/ktrk/story?section=news/health&id=8248600>



world

A father from the U.K. who lost his five-year-old daughter to Spina Bifida is now planning to cycle 1,000 miles in her memory.

Inspired by his daughter who “pushed herself beyond all limits,” Matt Allen aims to raise £10,000 for families in similar situations.

http://www.knutfordguardian.co.uk/news/9148800.Father_to_cycle_1_000_miles_in_five_year_old_daughter_s_memory/



2011-2012 Scholarship Recipients

From the SBAIL Yearbook

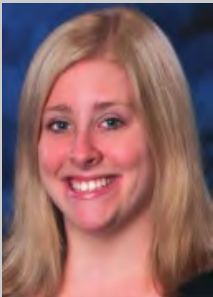
Every year, the Spina Bifida Association of Illinois offers financial scholarships to persons with Spina Bifida who are pursuing a post-secondary education. Applicants must reside in Illinois, have Spina Bifida, and have a demonstrated desire to help others. SBAIL also offers the [Valiant Scholarship](#), a \$2,500 award given to the applicant who best displays outstanding leadership, good will toward those less fortunate, dedication to making a difference in their communities, and the best demonstrated ability to help others with Spina Bifida.

All of the 2011-2012 scholarship recipients have impressive resumes. *Crossroads* proudly introduces them and their achievements!



Kendall Gretsch, *Valiant Scholarship Winner, Washington University in St. Louis*

Kendall is beginning her second year of study at WashU. She is majoring in biomedical engineering and has a remarkable 4.0 grade point average. On campus, she is also involved with Engineers Without Borders, Engineering Council, and Alpha Omicron Pi. Congratulations on your success and the Valiant Scholarship, Kendall!



Elizabeth Conroy, *Saint Ambrose University*

Elizabeth is working towards her master's degree in Speech and Language Pathology. Her bachelor's degree is in elementary education and she hopes to work in an elementary school to help children with articulation and language disorders. Last semester, Elizabeth was involved in the National Student Speech Language Hearing Association, which promotes professional interest among SAU students in these fields.



Adam Jomant, *Joliet Junior College*

Adam is a 2011 graduate of Lockport Township High School where he was an ROTC Drill Team Commander and received the Military Order of the Purple Heart award. He is also a member of the Will County Sheriff Explorers and the Sons of the American Legion. He is looking forward to starting classes at JJC in the fall and would like to be an electrical engineer.

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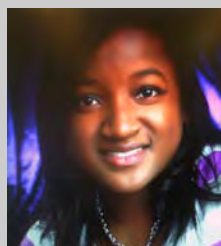
2011-2012 Scholarship Recipients

continued from page ten



Megan Johannsen, *Joliet Junior College*

Megan is attending Joliet Junior College. She has participated in many extracurricular activities like the Girl Scouts of America and several musical bands. She was also a statistician for boys' and girls' soccer teams. She was the secretary and treasurer for the Thespian Society Troupe and winner of the Ambassador Girl Scout Religious Award.



Christina King, *Robert Morris University, Springfield*

Christina King is now in her second year at RMU on her way to becoming a photographer for a publishing company. During her first year at RMU, she was named to the Dean's List and also received two awards: Family & Consumer Science Outstanding Student Award and Yearbook Production Business Manager Award. Christina is excited for another strong year.



Matie O'Connor, *Illinois State University*

Matie is a 2011 graduate of Regina Dominican High School where she received a Perfect Attendance Award each year and graduated with a 4.22 GPA. She is a Girl Scout and has been given the President's Award and the Gold Award from the organization. She has also worked extensively with Misericordia and Y-Me since 2003 and is excited to begin college in the fall.

Additional Scholarship Recipients



Jennifer Bradtke
Illinois State University



Jonathan Wesley
South Suburban College



Guadalupe Solorio
South Suburban College

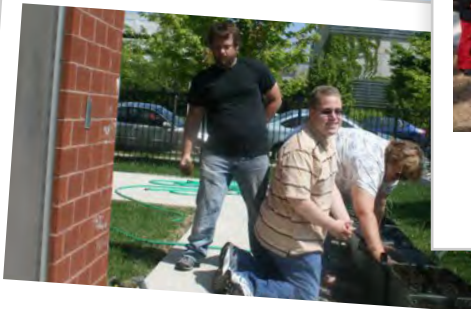
“The Greening of Anixter” Garden Project

From the SBAIL Photo Album

This spring, the Spina Bifida Association of Illinois and its partners, the [Kiwaniis Clubs of Illinois-Eastern Iowa](#), began a new project at Anixter Village called “The Greening of Anixter.” The project is centered around a brand new, enabled garden in the back lot of [Anixter Village](#), a one-of-a-kind apartment complex designed specifically to ease the transition to independent living for young adults with Spina Bifida.

The garden is fully accessible and cared for by [Anixter Village residents](#). Eventually, the residents hope to open a farmers market to sell the produce they grow in the garden. By helping the tenants develop this enabled garden and farmers market project, SBAIL is helping the residents acquire valuable vocational skills, improve their nutrition and living space, and manage responsibility.

Below are pictures from the garden. Crossroads would like to thank Carolee Stanmar and the [Association of Indian Pharmacists in America \(AIPhA\)](#) for the photos. Feel free to visit our [Facebook](#) page to see more pictures!



May 2011
SBAIL



April 2011
SBAIL



July 2011
AIPhA



July 2011
AIPhA



July 2011
AIPhA



July 2011
C. Stanmar

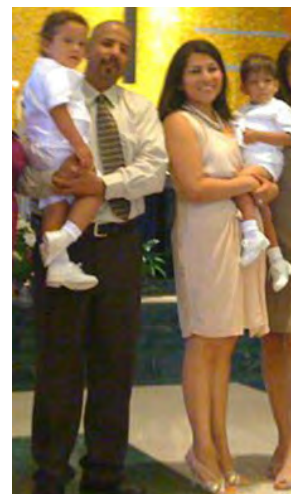
What SBAIL Means to Blanca Jara

Knowledge is power

Blanca Jara went to her 20-week ultrasound eager to see images of her twin babies. However — as many parents of children with Spina Bifida can relate — she left feeling lost and scared. Based on the shape of one of the babies' heads, doctors could tell that one of the twins had Spina Bifida.

“You always think your kids are going to be fine and perfect and have ten fingers and ten toes when you become pregnant, so hearing that Luis would have Spina Bifida was devastating. My husband and I gave ourselves one week to mourn and then we went out and educated ourselves. It was around this time that we found SBAIL.”

Blanca became involved with SBAIL through the outreach programs that SBAIL offers to new parents. “SBAIL has information that we needed and awesome outreach.” But Blanca's involvement changed drastically after she got her footing once the twins, Luis and Joaquin, were born in 2009. She cites her career and Luis as her motivation.



“The large turn-out of Latinos at the first Play Date event shows how much that population craves access to these resources.”

“Working in the public sector for the Cook County Circuit Courts has opened my eyes to how blessed we are just to have medical benefits and the means to get information. And, after having a baby with Spina Bifida, we realized how important family is and that we had the opportunity to help families who aren't blessed with the same means as our family. Having Luis really changed our family for the best.”

Since then, Blanca's role in SBAIL has only increased. She joined the board of directors after meeting board member, Javier Salas, and has translated resources on [SBAIL's website into Spanish](#). She's also worked on event committees for the [Chicagoland Bowl-A-Thon](#), the [Fall Family Classic](#), and the [Halloween Disco Party](#) and has been very active with the new [Play Date](#) program. Blanca's involvement with the Association has been absolutely essential in helping SBAIL increase its outreach to the Latino population, the ethnic group most commonly affected by Spina Bifida.

“The large turn-out of Latinos at the first [Play Date](#) event shows how much that population craves access to these resources and information and the fact that Latinos are most commonly affected proves that there needs to be more awareness within the community.”

Despite how much Blanca's involvement with SBAIL is helping other families, Blanca also feels that being involved with SBAIL helps her family.

“SBAIL's family-oriented events give Luis an opportunity to grow up in an environment where he won't be an outsider and will grow up with self-esteem. It will also make him more knowledgeable about his health and he'll be better equipped to help educate his peers about it, too.” ❖

Meet Josie Ostrander

Fall Family Classic Committee Member & Grandmother



The second you start talking to Josie Ostrander, you realize that she's an outstanding grandmother. When she talks about her granddaughter Hannah, a six-year-old who was born with Spina Bifida, her voice fills with tones of gentleness and joy that only a grandmother can emulate.

When Hannah was a little over a year old, Josie and her family began looking for ways that they could show their support for Hannah. In their search, they came across [SBAIL's website](#). "We wanted to get involved and volunteer so we could support this little girl. We wanted to learn more about Spina Bifida and make life as fun and normal as possible for her." SBAIL — especially the [Fall Family Classic](#) — seemed to offer them these possibilities.

However, Josie's involvement with the Association did not stop at attending events or searching for information

on [sbail.org](#). Instead, Josie's involvement escalated and, last year, she even joined the [Fall Family Classic](#) Committee and used her position as an opportunity to spread awareness of Spina Bifida. "When SBAIL functions come up, I hand out the flyers and send out emails to a pretty big group of friends to encourage them to attend the events. It's just a little way I can be involved."

Josie was selling herself short, though; volunteers like her are what truly makes SBAIL successful at raising awareness of the disease and being a comforting resource for those affected by Spina Bifida. "SBAIL is such a great organization and I'm so glad I got involved. The fundraising is so important and the [website](#) is so knowledgeable and has so many resources available so we can find assistance for Hannah whenever we need it."

Josie's close relationship with her granddaughter has made her realize how important physical, social, and emotional support is for families affected by Spina Bifida. "Over the past few years, I've come to learn what it's like to be in the life of someone with Spina Bifida and how disabling the disease really is. It's made me realize that I have to do whatever I can do to help." ❖

“SBAIL has so many resources available so we can find assistance for Hannah whenever we need it.”

Chicagoland Bowl-A-Thon



The 2011 Chicagoland Bowl-A-Thon was held at [Poplar Creek Bowl](#) in Hoffman Estates. The two-day event raised \$22,500 for individuals and families affected by Spina Bifida. The 220 attendees enjoyed an afternoon of free bowling, pizza, pop, beer, and a silent auction and raffle. Bowlers also received an official event tee-shirt. The event was fun for the whole family and raised money and awareness!



Jenny Nilsen

Proactive Fundraiser & Inspiring College R.A.

Jenny Nilsen has been involved with SBAIL for longer than she can remember. Born with Spina Bifida, Jenny has been attending SBAIL's Christmas parties and camps since she was a small child. As Jenny got older, though, she became more involved with helping SBAIL deliver the same services and programs she had benefitted from as a child.

In high school, Jenny began to "give back" to the community that she says has given her so much. She had previously attended Camp Ability as a camper, but returned as a volunteer one year to make the experience as valuable for younger children as hers had been. She also made rubber bracelets similar to the Livestrong bracelets and sold them to her friends during her sophomore year. The bracelets read "WillStrong" and were designed to raise awareness of Spina Bifida. She then donated the proceeds from the sales to SBAIL.

In college, though, Jenny found ways in which she could become an even bigger advocate for SBAIL and for others with disabilities. As a resident assistant at [Bradley University](#) in Peoria, Jenny realized that she was in a position where her voice could be heard.

“I wanted to help future students who might not be able to advocate for themselves in the same way I could as an R.A.”

“I was frustrated during my freshman year because I was having accessibility issues with the campus. As an R.A., though, I was able to use the position to help the University improve its accessibility. I wanted to help future students who might not be able to advocate for themselves in the same way I could as an R.A.”

But being an R.A. did not only pay off because of how it helped her work with the University towards total accessibility. The connections she made with her residents were also valuable. During her junior year of college, several of the girls in her hall volunteered to help organize a fundraiser during Spina Bifida Awareness Month.

“I saw a need to get awareness out about Spina Bifida, so a few of my residents and I began selling the WillStrong bracelets I sold during high school. I wanted them to know me a little better and they all seemed interested in learning more about Spina Bifida. It actually turned out that a girl on my hall was born with Spina Bifida Occulta and had been diagnosed with it at fifteen. The fundraiser really worked to help connect the whole floor.”

The fundraiser was a huge success. Not only did it raise awareness of Spina Bifida at Bradley University, but it also raised a lot of money for SBAIL.

“SBAIL is so important. This fundraiser was just a way for me to gently raise awareness among my peers and donate whatever money I could to SBAIL which has done so much for me. It's been a support system for me throughout my life, it's how I met my best friend in the entire world, and it's given me opportunities I may not have had if SBAIL hadn't been promoting those opportunities.”❖



Meet Michell Haase

TravelinWheels Founder, Adventurer, & Mother



Michell Haase aims to make accessibility information more accessible. Her company, [TravelinWheels](#), researches the accessibility details of hotels, restaurants, attractions, tours, transportation and medical providers around the world. Her website, www.TravelinWheels.com, offers all this information as well as virtual tours and the ability to book travel online for people with mobility, sight, hearing, and stature difficulties.

Michell says the idea for the company has been growing with her daughter, Kelsey, who is 18 years old and was born with Spina Bifida. Kelsey is an accomplished adaptive athlete and travels frequently for competitions. During their struggles planning these trips, Michell and Kelsey realized that there was a lack of thorough, objective information on accessibility travel.

“I saw all the positive effects adaptive sports and travel have had on Kelsey. It gives her chances to see the world and realize everyone has some type of disability, not just her. [TravelinWheels](#) gives us the opportunity to enable other people to travel confidently and comfortably so that they can acquire the same benefits Kelsey has.”

[TravelinWheels](#) hopes to encourage, inspire and enable people with disabilities to travel by helping them identify their travel options. The company serves as a resource for people with disabilities and has a wealth of information, from the accessibility of Chicago-area restaurants to exotic parasailing programs in Hawaii and Sherpa-aided hikes up Mount Kilimanjaro for people with disabilities.

Michell is well aware of the importance of resources for people who are facing daunting struggles. She first found SBAIL when she found out that her daughter would be born with Spina Bifida and believes that connecting people and information is essential for people rise to a challenge.

“SBAIL is a tremendous resource. It was the first place I called when I found out my baby was going to have Spina Bifida. I didn’t even know what Spina Bifida was and they connected me right away with Dr. McLone and other families with children with Spina Bifida. SBAIL gave me a great community that I’ve had since before Kelsey was even born.” ❖

“TravelinWheels gives us the opportunity to enable other people to travel confidently and comfortably.”



Candlelight Bowl

The 2011 Central Illinois Candlelight Bowl was held at [AMF Circle Lanes](#) in Bloomington, Illinois. All the lanes were filled and the event raised over \$4,500 to help fund SBAIL’s local support groups and other programming. Attendees enjoyed three games of candlelight bowling, an auction and raffle, and free pop, popcorn, and pizza.



Dr. Matthew Richmond

SBAIL Board Member and Adult with Spina Bifida Awarded Psy.D. Degree

Matthew Richmond, Psy.D., has spent his life serving as an advocate for people with Spina Bifida.

Dr. Richmond was born with Spina Bifida and, as a child, sometimes felt isolated and let-down by the education system. During this time, Dr. Richmond learned the important role self-advocacy would play in his life. Since then, he has navigated complex social systems and become a strong advocate for others. He has applied these skills to his professional career in clinical psychology. In doing so, he has served as a proponent of institutional change at a variety of levels with numerous organizations. He also works to help others with disabilities become “agents of their own change.”



His substantial academic accomplishments ultimately lead to him becoming the first recipient of SBAIL’s Valiant Memorial Scholarship. Despite these achievements, Dr. Richmond’s Spina Bifida sometimes impacted his education. Even in graduate school, he continued to notice subtle differences between his learning style and that of his

classmates. “My interest in health psychology, advocacy, and education stems from my experience as a student with some unique learning differences. Early on, I struggled to find an independent voice and sense of direction within the education system. Thus, I felt the need to self-advocate where it would have been more ideal for the system to play a large role,” Dr. Richmond said. Even as an adolescent, Dr. Richmond understood that education could not simply be offered in a “one size fits all” format. As a healthcare professional, he has made advocacy-related psycho-education a priority.

“I promote dialogue that incorporates disability into the mainstream discourse on diversity.”

Realizing that he wanted to help students with disabilities become change agents, Dr. Richmond pursued a doctoral degree in clinical psychology and received his doctorate from the [Chicago School of Professional Psychology](#) in June of 2011. He shares, “My foremost professional goal has always been to further explore how notions of

disability and empowerment could interface in a more seamless manner. I strive to be in a position as a mental health professional from which I can act across multiple systems in an effort to advocate for change. It is imperative that we, as a society, continue to promote a dialogue that would further incorporate disability into the mainstream discourse on diversity.”

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Windy City Corvettes Raffle

The 2011 Windy City Corvettes car show and raffle was a huge success! The raffle nearly sold-out and one lucky winner walked away with a brand new 2011 black Corvette Coupe!

The proceeds from the raffle benefitted SBAIL. The Windy City Corvettes have donated over \$610,000 to SBAIL since their first Corvette raffle in 1992. Thanks so much, Windy City Corvettes!



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Dr. Richmond has served in the leadership of our organization as a member of the SBAIL board of directors since 2006. He has worked with the Association to strengthen its family networking efforts and to add a more clinical focus to its programming. Through this work, Dr. Richmond has promoted the importance of balancing practicality and fun when developing specific events for our members.

“We need to work toward a systematic paradigm shift that removes individuals with Spina Bifida from an exclusively medicalized framework. To this end, it is important that SBAIL’s programmatic efforts be facilitated with a balance in mind between clinical goals such as independence and self advocacy and an explicit effort to make the programs fun. As such, participants and their families can follow this balanced approach in learning how to lead happy and productive lives.”

Those seeking special education advocacy services at an IEP meeting, executive functioning support, psychotherapy, transition consultation, neuropsychological evaluation, or other related services for infants, children, teens or adults with Spina Bifida or another special healthcare need or disability are welcome to contact Dr. Richmond for more information. He is currently a Postdoctoral Fellow in Behavioral Health Psychology at Primary Care Psychology Associates, LLC (PCPA), which is the cooperative partner for psychological services of [Northwestern Memorial Physician’s Group \(NMPG\)](#). The practice has several offices throughout the Chicagoland area.

Dr. Richmond is an expert in bilingual assessment and treatment, and can provide all services in both Spanish and English. He can be reached for more information at (847) 421-0122 or via email at drmattrichmond@gmail.com. ❖

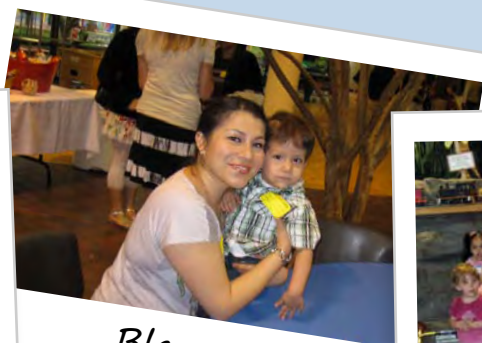
May 21st “Play Date” Outing

From the SBAIL Photo Album

SBAIL has started a new program called Play Date. The program meets monthly at [Shriners Hospital for Children, Chicago](#), and targets children under five with Spina Bifida and their parents and enables networking and safe, accessible play. Please email Faith Morgan for more information on future Play Date events at fmorgan@sbail.org.



Kids at
Play



Blanca &
Luis Jara



Group
Photo

from our friends...
news & information

Wheelchair Basketball

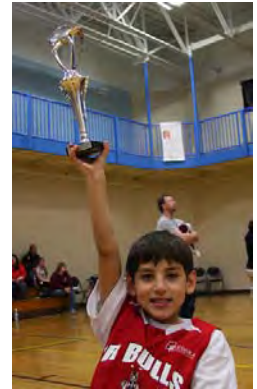
Saturdays, Oct. 1st to March 3rd, Noon-2pm



NEDSRA is excited to announce its wheelchair basketball programs. They have options available for athletes of all skill levels.

Athletes must have a physical disability, be between the ages of 5 and 21, and be willing to use a sports chair (And NEDSRA has plenty of sports chairs available for participant use!) in order to participate.

Contact **Adam Kramer** at (630) 576-4037 to register or for more information.



Dr. House's Radio Show

Tuesdays from 1-2pm



TravelinWheels is excited to announce that it will begin broadcasting on **HealthRadio.net**. They will work with the weekly online, interactive talk show "Dr. House: Living with and Beyond Disability." TravelinWheels will serve as a Travel and Lifestyle correspondent for the radio show.

The show and TravelinWheels's bi-monthly segments promise to be informative for all affected by Spina Bifida.

TravelinWheels first appeared on the show on Tuesday, August 9th. Dr. House's show airs online every Tuesday from 1-2pm Central Time and TravelinWheels will be on the show every other week.

GLASA's Fall Programs

See their online event calendar at:

http://glasa.org/index.php?option=com_events&Itemid=143

GLASA provides year-round sports and recreation programs for youth and adults with a physical disability or visual impairment.

Some of the adaptive sports they offer include judo, football, tennis, golf, horsemanship, softball, swimming, and track and field.

Visit their website, www.glasa.org, for more information on registering for these programs.





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