Lifesharing
Family - "We Belong Together"
President’s Message

Dear Friends,

It is always gratifying to have your efforts recognized by those outside of your organization. That is why we were very honored by two recent awards that reflect on the values and philosophy that are so evident throughout the Barber National Institute. The first was the presentation of the Temple Grandin Award by the Autism Connection of Pennsylvania that was so richly deserved by Dr. Maureen Barber-Carey. This honor is given annually to the “individual who has most clearly contributed to maximizing the potential and possibilities of children, adolescents and adults with autism.” This definition certainly describes the life’s work of Dr. Barber-Carey, who has and continues to make a significant impact on the lives of individuals with autism and other intellectual disabilities, as well as their families.

We were also proud to celebrate a national award for innovation presented by the National Association of Private Special Education Centers. This honor recognized the artist-in-residence program that enables our students and faculty to enhance their technology skills by creating digital books and animated movies with digital artist Jude Shingle. It is an example of the wonderful work that can be achieved when we collaborate with civic minded donors such as First Niagara Bank and Erie Arts and Culture.

We’ve had more cause for celebration as several more adults in our Supported Employment program recently found jobs in the community. We are grateful to businesses in our region that open their doors and provide adults with opportunities to show that they can become dedicated and loyal members of the workforce.

I also want to express appreciation to Erie Insurance for a $120,000 matching grant to help fund a new wireless infrastructure that will link all 49 Erie group homes to the electronic records system throughout our organization. This will vastly streamline operations and improve the care that we provide to more than 200 adults residing in our homes. We are now looking to our generous donors to help us fundraise to match the grant and completely fund this project.

With summer finally here, we are happy to welcome youngsters, adults and staff who are joining us for a variety of camps. While all of our programs benefit from the generous contributions of our donors, our bike camps in Erie and Warren and the before and after care portions of our Connections Camp for children with autism are completely funded by gifts to the Barber Foundation. Even though it is summer vacation—the gifts from our donors are still hard at work!

With wishes for a happy and safe summer, and sincere thanks for all that you do to help our children, adults and families in making dreams come true.

Sincerely,

John J. Barber
President & Chief Executive Officer

Mission Statement

We “Make dreams come true.” We provide children and adults with developmental disabilities and their families the education, support and resources needed to be self reliant, independent and valued members of their community. In addition, we provide the professionals who serve them with world-class education and training.

Congratulations to 2015 Shillelagh Man of the Year, Robert Marz (far right). Pictured from left: John Barber, president of the Barber National Institute, Bridget Barber, Director of Health Services, External Affairs & Privacy Officer, and Gerrie Marz, Robert’s wife. The event was a success thanks to the generosity of the sponsors and the more than 30 foursomes participating.
Volunteerism Key to Club Erie

Every week, a group of adults in Club Erie prepares for a community dinner at the Church of the Covenant. They set the tables, prepare the buffet, and assemble fruits and vegetables for a salad bar. But for this particular dinner, they were the guests of honor, and would be recognized for their dedicated volunteerism throughout the year.

“Your help preparing our weekly community dinner has been greatly appreciated,” said Joseph Kumer, director of youth and family ministries at the Church of the Covenant, in an invitation to the dinner. “You set our tables with great care, and our salad bar would not happen without all of your work. Our cooks could not do it without you.”

The Church of the Covenant is one of several sites where adults in Club Erie regularly volunteer, preparing the weekly dinner that is attended by many college students and recent immigrants who live in its downtown neighborhood.

Groups have also been going to the Food Bank at Saint Patrick’s Parish for the past several years to assemble food boxes for the hundreds of families served by the pantry every week. They also play bingo with residents at Sunrise Assisted Living Center, sort food for the Second Harvest Food Bank, tag clothing at the Salvation Army and stuff informational packets for the Juvenile Diabetes Association. Another adult volunteers with a Club Erie staff every week at the Tom Ridge Environmental Center.

Volunteering is one option that adults can choose to take part in. Other weekly offerings at Club Erie include recreational activities such as bowling, visits to museums and other community sites, or skill building activities such as computer classes.

“Our staff present the choices and explain that this is something that they can do to give back,” said program specialist Jeanette Metzler. “A lot of adults choose a volunteer opportunity because they like working as part of a team and enjoy the camaraderie that comes with volunteering.”

Club Erie activities, including volunteerism, are designed to foster independence, promote community access and teach social skills. “It can also be a good foundation for building job readiness skills and be a valuable addition to a resume if the adult moves into supported employment,” said Jeanette.

Volunteering is also an option as part of the Community Endeavors program in Philadelphia, where adults assist at the Elkins Park Hospital by helping clean in the cafeteria, and assisting in clerical work in the offices. Also, adults and staff collect and deliver shredded paper used in the animal cages at the SPCA.

At the recognition dinner, adults were invited to bring two guests and were presented with a certificate and a $10 Wal-Mart gift card. But, that’s not the real reason they volunteer. “They are also proud to say that they are helping someone else,” said Jeanette.

So, the experience becomes a “win” for the adults and for the organizations they work hard to help.

Volunteers prepare for a community dinner held weekly at the Church of the Covenant.
Like most eight-year-old girls, Enji Shukur loves singing music from the movie “Frozen.” What makes that so remarkable is that less than two years ago, she arrived in the United States unable to speak English, without a wheelchair and having never been in school.

Today, after working with faculty and therapists in the Elizabeth Lee Black School, Enji is speaking and reading the language of her adopted home, is a wiz on the iPad, and is learning to use her own power chair.

“She is really like a sponge, just picking up new things every day,” said teacher Julie Moore. “She retains everything that she sees and hears.”

Enji is one of nearly 20 students in the Elizabeth Lee Black School who have emigrated over the last several years from other countries, primarily in Eastern Europe, Asia, the Middle East and Central America. Most have language barriers to overcome in addition to the challenges posed by their disabilities.

“When an international student comes here, most receive speech communication therapy,” said speech-language pathologist Stephanie Rose Briggs. “In order to learn, we have to find a way for students to communicate.”

For many students, admission to the Elizabeth Lee Black School is the first time that they will receive any educational or therapeutic services. “Many of the countries don’t have services or facilities for children with disabilities,” said Cindy Priester, education program coordinator. “So our faculty has become really creative in addressing a variety of issues that some of the students have, in addition to responding to their learning problems and physical disabilities.”

Many families, including Enji’s, have endured long struggles to come to the United States. Enji left Kirkuk, Iraq, with her mother and sister in 2011, and then lived for more than two years in a refugee camp in Turkey. Enji, who has cerebral palsy, did not have access to school and did not have a wheelchair.

Arranging to get needed equipment is also a challenge for faculty. When Enji began school, staff worked to get a wheelchair, braces and other devices she needs to promote mobility and reduce spasticity in her legs. Another international student, who is both visually impaired and in a wheelchair, is learning to use a device with switches to make requests.

Faculty members are also resourceful in teaching language skills and basic education, often using pictures and music to help students learn English. “We sang a lot of things, which Enji loves, and she picked up a lot of language through music,” said Julie. “We would ask her to repeat everything that we said, and even after hearing something just once she remembered the words. Now, she is speaking in full phrases and even sentences.”

Enji listens intently to the communication devices that her classmates use, and is using the iPad to learn the alphabet, numbers and other concepts. She also receives speech, physical and occupational therapies every week.

For many international students, opening up and adapting to a new culture takes time. Emily Landkrohn, a speech pathologist who has worked with Enji, said she started off shy, but now is “really blossoming with her language.”

Like all students, international youngsters are the latest to benefit from the philosophy of the Elizabeth Lee Black School that says “if a child can’t learn the way we teach, we will teach the way a child can learn.” For faculty, this reflects their commitment to develop the most innovative, creative ways to make every student’s dreams come true.
When Frank Amoroso passed away, he left behind cherished memories for many close friends. Few people would have expected the 82-year-old retired craftsman to also leave a legacy that will improve the lives of children with disabilities for years to come.

But that is the impact from a $250,000 gift designated in Mr. Amoroso’s estate to the Dr. Gertrude A. Barber Foundation following his death in September, 2013.

A Corry native, Mr. Amoroso served in the United States Marine Corps during the Korean War. Upon returning home, he became a skilled cabinet maker and worked for area businesses. While employed in the maintenance department at Hamot Medical Center (now UPMC Hamot,) Amoroso often visited the nursery during his lunch hour. There, watching premature babies, friends say he developed empathy for children who struggle to overcome challenges.

“Mr. Amoroso’s generosity will mean that, far into the future, children with disabilities will be benefiting from this gift,” said John Barber, president of the Barber National Institute. “Once again we see the impact that one person—who by all accounts led a quiet, modest life—can have on the lives of so many others.”

Estate gifts can be made in the form of cash, stocks, insurance policies or property. For more information about arranging for an estate gift, contact the Barber Foundation at 814-874-5640.

“Compassion for Children Inspires Estate Gift”

Every Friday for the past 3½ years, Dustin Nesbitt has volunteered for Meals on Wheels. He packs the food with care, and knows the names of all of the people on his delivery route. At Christmas, he even buys gifts for some of the clients “to make them feel blessed.”

In recognition of his volunteerism for several community groups, Dustin was nominated for the RAVE Awards presented by the Jr. League of Erie to honor dedicated volunteers in the community. In being nominated for the award, he expressed pride in his accomplishments and the person that he has become today. “Making a difference is very important,” said Dustin. “The community has helped me, so I want to give back to the community.”

The path to Dustin’s transformation began four years ago when he went to live with James Finney and Stephanie Fabian in the Lifesharing through Family Living Program sponsored by the Barber National Institute.

Lifesharing is a program that enables an individual with a disability to join a provider family or companion, in their private home, as a fully participating member of that family.

Lifesharing providers can be single adults, families with children, or “empty nest” couples such as Stephanie and James. Stephanie worked as a special education teacher in an autistic support classroom for many years. Her dedication to ensuring a quality of life for people with disabilities far exceeded her classroom responsibilities. Even after her students graduated, Stephanie continued to connect them with services in the community.

Stephanie wanted to continue giving by opening up her home to a young man with autism. As providers, Stephanie and James form a cohesive partnership in which their attributes balance one another to form a dynamic duo. Their partnership, along with Dustin’s drive and motivation, has helped Dustin mature into a happy, polite, peaceful and giving young man.

Following in the couple’s example of service to others, Dustin has dedicated much of his time to giving back to the community. In the past year, he has spent more than 580 hours volunteering for a variety of organizations, including Orphan Angels Cat Sanctuary, Salvation Army, the Maritime Museum, Meals on Wheels, The City Mission Second Harvest Food Bank, and McLane Church.

For Bethany Kalie, Dustin’s Lifesharing program specialist, the opportunity to work with a devoted and genuinely compassionate young man such as Dustin has been very rewarding. “His personal transformation is beautiful and truly inspirational,” said Bethany. “But we would not be able to celebrate Dustin’s achievements if it were not for Stephanie and James. I am constantly in awe of their dedication, benevolence, and altruistic nature. Stephanie, James, and Dustin exemplify what Lifesharing is all about.”

To learn more about the Lifesharing through Family Living program, visit www.barberinstitute.org or call Bethany Kalie, Lifesharing Program Specialist, at 814-874-5609.

“Lifesharing Family Promotes Volunteerism”

“How can we expect our children to know and experience the joy of giving unless we teach them that the greater pleasure in life lies in the art of giving rather than receiving?” ~ James Cash Penney

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The Beast Beckons

“The layout and the course were perfect. Obtainable by the most seasoned athlete to the people who have never done an obstacle course.”

“I absolutely loved this course! It was challenging but not extreme to the point where I couldn’t complete it.”

“Best challenge of my life!!”

“It was a lot of fun and for a great cause!”

“Can’t wait for Sept. 12, 2015!!!”*

What are these people so excited about? It’s the 3rd annual Barber Beast on the Bay at Presque Isle State Park—a ten-mile course of sand, trails and water and more than 20 challenges that will have you climbing, crawling and slogging your way to the finish line at Waldameer Park. And, there’s the one-mile Interim Healthcare Adapted Course for adults with disabilities.

If you would like a free or reduced price registration, and support the mission of the Barber National Institute, sign up as a Beast on the Bay fundraiser!

Get your friends together and register as a team, or go it alone—either way, it is an experience you won’t forget! Not ready to beat the Beast? Here are some other ways to get involved in this fun event:

• **Volunteer.** You can choose from staffing water and nutrition stations, monitoring obstacles, registering participants, and other assignments.

• **Form a Cheer Zone.** Sign up your group to cheer on participants along the course and compete for prize money for your organization.

• **Become a sponsor.** Businesses and organizations can choose from an array of levels by contacting Laura Schaaf. It’s a great way to get your business involved with an awesome event, and support a good cause.

More information is available by calling 814-480-6810, or at www.BarberBeast.org

*Comments from the 2014 participant survey

What’s new in 2015?

New things are happening every day! Here are a few things in store:

• Our final obstacle will be in the new wave pool at Waldameer.

• The adapted course will be held inside Waldameer Park, bringing participants closer to the hub of activity.

• Participants in the 10-mile course and the adapted course will have the same finish line, bringing the two events together for a spectacular ending!
Fundraising Phenom

Patrick Eller has been the top fundraiser for the Barber Beast on the Bay for two years, and has no plans to relinquish his crown. In fact, standing from atop his perch as lead fundraiser, he has challenged many others to get involved.

“When I started, [I read] that you had to raise $550. But when I looked at it, it said really that all you had to do was pay the cost of the race if you didn’t raise that,” he said.

“I’ve learned that people love to give to charity especially when you tell them you’ll be doing something for that charity with the money they’re giving,” he said, before adding, “I challenge people to become fundraisers. Don’t just pay the $50. Don’t just pay the $100. Actually go out there and raise the money. Earn your entry.”

Or, if you’re like Desiree Davis, who has already paid for her registration, work to raise funds anyway. “I am really working to raise funds for the Beast. I am running the race in honor of my brother and a friend, both of whom have Down syndrome,” she said. “Currently they are not in good health. I am motivated to share the joy that these two individuals bring to my life.”

To see video messages from Patrick Eller, visit www.youtube/user/TheBarberInstitute.com

Raising Funds at the Highmark Walk

The Beast joined Barber National Institute staff and family members for the 10th Annual Highmark Walk for a Healthy Community on Saturday, June 6, 2015. Thanks to all our walkers and donors who were able to raise $1,640 for the Barber National Institute!
The 2015 Dr. & Mrs. Robert Guelcher Art Show at the Barber National Institute was the largest exhibit in the event’s eight-year history, with work from 185 youth artists as well as 262 adult amateur and professional artists from across the region.

More than 1,000 guests visited the four-day exhibit, where many of the works were available for sale. Three judges from the local arts community reviewed the more than 500 pieces of artwork featured in this year’s show that included sculptures, paintings and mixed media. The following awards were presented:

**Adult Professional Artist**

Best of Show: Brenden Daugherty, “Intent”
Honorable Mention: Thomas Ferraro, “Easter Parade”
Deborah Sementelli, “In the Corn”
Barbara D. Crone, “Save the Penguins!”

**Adult Amateur Artist**

Best of Show: Rebecca Merry, “Just Out of Reach”
Honorable Mention: Lawrence Nies, “Midnight at Siegel Marsh”

**Adult Professional Photography**

Best of Show: Jarid Barringer, “Time and Space”
Honorable Mention: Fred Olds, “Houseboat Horseshoe Pond”

**Adult Amateur Photography**

Best of Show: Robert Raydo, “Abandoned”
Honorable Mention: James Rutkowski, “Sea Grass Sunset”
Terry Pytlarz, “State News”

**Youth Artists**

Best of Show: Sophia Tang, "Jiang Nan (South Shore)"
Honorable Mention: Christian Kakulu, “Dusk in the Mountains”
Andrea Hecker, “Awareness Grows”

**Youth Photography**

Best of Show: Kaely Carlson, “Walking Down the Street”
Honorable Mention: Mike Wassolu, “7 Miles”
Isabelle Southard, “Winter Flyers”

Winners of the People’s Choice Award voted on during the show were Rebecca Merry in the adult category for her paper sculpture, “Just Out of Reach” and Abby Mercatoris-Morrison, a student at Villa Maria Academy, for her drawing in charcoal, “James Lafferty.”

Artists and art appreciators are encouraged to mark their calendars for the 9th annual show and sale scheduled for April 8-11, 2016.
New IT Project Improving Care for Adults

Take all the logs of information that span hundreds of written pages and convert them to an electronic document. Take the time needed to inform others about medical issues or behavioral challenges and make it instant.

Both are the benefits anticipated from “Connecting to the Future,” the project that will provide a new wireless infrastructure throughout the Barber National Institute, including 49 Erie group homes, enhancing the quality and continuity of care for more than 200 adult residents.

The project is becoming a reality with a $120,000 matching grant awarded by Erie Insurance. Now, the Dr. Gertrude A. Barber Foundation is looking to donors in the community to fund the remaining amount.

The new system will replace the paper logs of handwritten information that often exceed hundreds of pages and must travel with residents as they go from their residential homes to day programs or medical appointments. The new capabilities will transition current paper-based records over time with electronic records.

In addition, staff would be able to share important information about medical issues or behavioral challenges in real-time to more effectively respond to the needs of the adults.

Other benefits of the project include:
- Immediate recording of vital information into CareLogic, the Barber Institute electronic health records system.
- Ability to collect and analyze data to create more appropriate programming tailored for the individual.
- Reduce time staff currently use to complete required documentation to enable more time to interact with residents.
- Long-term cost savings in transitioning from the paper-based system currently in use.
- Environmentally-friendly advancement that reduces paper, printer ink, etc.

For more information about making a donation to this project, contact Laura Schaaf, director of Giving at the Barber National Institute, at 814-874-5802 or LauraSchaaf@BarberInstitute.org.
**Success for Slater**

When Slater Shadeck began preschool just two years ago, he had very little functional language to express himself. Today, he is reading aloud on a first-grade level.

“When he started school, Slater was very shy and timid, and really did not have language,” said Nina Burkhardt, the teacher in the autistic support preschool class. “Today, he has very good reciprocal conversation skills, and will ask for help and initiate communication.”

Slater was among more than 40 preschool age students who graduated in June, ready to move on to kindergarten in their home school districts. For Slater’s teachers, this progress has been remarkable.

Faculty worked to build language and social skills, and Nina said he has grown “in leaps and bounds.”

Slater loves working on the iPad, playing games and putting together puzzles. “He has learned to talk to the other students to make them part of what he is doing,” said Nina.

The youngster also has always liked reading stories on the computer, and started making quick progress through basic reading materials. Now, he is mastering the beginning first grade readers.

Earlier this year, Slater began going to the Happy Hearts classroom once a week for interaction with typical peers. In the fall, he will be starting preschool in an autistic support kindergarten classroom in Millcreek, with the ultimate goal being full inclusion in a typical kindergarten classroom.

“It has really been amazing to see Slater go through this transition from when he began school to now gaining so much in his independence and confidence,” said Nina. “Slater’s family, his therapists and all of his teachers have worked very hard to help him achieve these goals, and get him ready to keep learning and growing.”

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**Robot Research Presented at International Conference**

The Barber National Institute behavior specialists leading the research collaboration with the University of Notre Dame presented preliminary project results at the International Meeting for Autism Research (IMFAR) held in May in Salt Lake City, Utah. Jennifer Musolff, MS, BCBA, and Dan Portenier, MS, provided an update on the study that tests the use of robots in therapy for children with autism.

Nearly 2,000 participants from more than 30 countries participated in the IMFAR conference that provides researchers from around the world with an opportunity to share the latest scientific developments in autism research.

The Barber National Institute began the collaboration with Notre Dame in May, 2012 to evaluate how robots can reinforce the development of social skills. After trials at the Barber National Institute conclude in the fall, Musolff and Portenier will work with Notre Dame researchers to prepare the results for publication. Early results from both sites indicate significant improvements in social skills development when the interactive robot is added to therapy, particularly for children over five years of age.

The Barber National Institute is planning to continue research by developing a protocol to test whether the robot can be effective when used in the classroom with groups of students.

The robot research is funded by a grant from the Dr. Gertrude A. Barber Foundation.

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**Pittsburgh Staff & Families Support Autism Walk**

Our behavioral health team was on hand for the annual Autism Speaks Walk held June 14 in Pittsburgh. Staff offered information for families and activities for children, and joined our families on the course to walk for a good cause.
The majestic Phipps Conservatory and Botanical Gardens in Pittsburgh was the site for the 2015 Temple Grandin Award presentation to Dr. Maureen Barber-Carey, executive vice president of the Barber National Institute. The award is presented annually by the Autism Connection of Pennsylvania to “the individual who has most clearly contributed to maximizing the potential and possibilities of children, adolescents and adults with autism.”

Dr. Barber-Carey, who was among 16 nominees for this year’s award, spoke about the experience of receiving the honor.

This award is named in honor of one of the country’s leading autism advocates. What does receiving an award named for Temple Grandin mean for you?

I am humbled to receive an award that has been named after one of Time Magazine’s 100 most influential people in the world. I too am a passionate advocate for children with autism and firmly believe that early intervention is critical. I also believe that a supportive teacher can make all the difference.

How did your journey with autism begin and what have been the milestones along the way?

My journey began as a teenage volunteer at the Barber National Institute. This experience fostered my desire to pursue graduate studies in special education. Later, as a special education supervisor in the late 80s, I began seeing more children with autism. I shared this with my aunt, Dr. Gertrude Barber, and she agreed that, as an organization, we needed to advance our skills to better serve this growing population. We initiated plans to bring autism experts to Erie, and to send our staff across the country for training so that we could become leaders in the best possible practices and methodologies for teaching children with autism. Of course, another large aspect of my journey has been when my son, Ryan, was identified with autism.

What kind of encouragement would you like to offer to parents and families who are living with the challenges of autism?

I always view my cup as half full, not half empty, and try to never focus on the negative. Some days may be harder than others, but I try to remember that whatever challenges I may face today, tomorrow is a new day that brings with it new hope and opportunities.

Hamot Health Foundation recently donated four Automated External Defibrillators, lifesaving devices used in cardiac emergencies, to the Barber National Institute. Laura Schaaf, left, director of Giving at the Barber National Institute, and Bridget Barber, director of Health Services, External Affairs & Privacy Officer, accepted the donation from Jason Chenault, Ph.D., senior director of Emergency Services, Ann Tredway, president of Hamot Health Foundation, and David Basnah, EMS specialist at UPMC Hamot. Two AEDs are installed on the main campus of the Barber National Institute, and the others are in place in the Institute’s facilities in Corry and Girard.

Calendar of Events

Millcreek Parade
(Look for Barber Beast on the Bay)
July 4

“Learn to Ride” Bike Camp
Saturdays, July 11 - Aug 1
Warren County YMCA, Warren

Disability Awareness Night with Pittsburgh Pirates
July 8
PNC Park

Erie Gives Day
Aug. 11

Barber Beast on the Bay
Sept. 12
Waldameer Park and Presque Isle State Park

Ladies Only Luncheon
Nov. 21
The Kahkwa Club

Barber Christmas Ball
Dec. 12
Bayfront Convention Center

The community is invited to support our events and activities. For information, visit www.BarberInstitute.org
School faculty, donors and members of the arts community celebrated the Award for Leadership and Innovation presented by the National Association of Private Special Education Centers. Dr. Maureen Barber-Carey, second from left, welcomed Michael Borowy and Lisa Slomski of First Niagara Bank, digital artist Jude Shingle, and Amanda Sissem, executive director of Erie Arts and Culture. The national award recognizes the artist-in-residency program that enables students and faculty to work with Shingle, a professional artist, to create multimedia publications such as digital books, movies and animations. The artist-in-residency program is funded by First Niagara Bank, Erie Arts and Culture and the Dr. Gertrude A. Barber Foundation. Every year, more than 60 students have the opportunity to be involved in the program.