Supporters of The Advocacy Center and LDA Life and Learning Services gathered for the Celebration of Champions fundraising event, held on Saturday, September 13 at Locust Hill Country Club.

The centerpiece of the evening, the presentation of the 2014 Community Awards, celebrates individuals and organizations making a difference in the lives of individuals with disabilities.

Co-Emcees Don Alhart and Jennifer Johnson of 13 WHAM-TV along with Senator Ted O’Brien, Senator Joe Robach and Assemblyman Mark Johns, presented the Community Awards. The event featured a silent auction, a wine pull, and music provided by The Mambo Kings.

Proceeds of the evening support programs at both agencies. The Advocacy Center and LDA’s first Celebration of Champions as partners was a great success!

Please see page 2 for profiles of the Community Award winners.
Celebration of Champions

2014 Community Award Winners

Community Impact Award
Mariellen Cupini

The Community Impact Award honors an individual or organization creating inclusive opportunities for individuals with disabilities. This year’s recipient is Mariellen Cupini, CEO and Founder of Stepping Stones Learning Center.

Mariellen Cupini founded Stepping Stones Learning Center in 1994 with a goal of providing early childhood education for children with and without special needs, from birth to age 21. The Center offers a wide range of services including speech, occupational and physical therapies, and other clinical services. Mariellen and her staff are also working to address the gaps in child care for working parents of children with disabilities. This fall, the center plans to offer a fully-inclusive full-day child care and after school program. Mariellen is commended for creating an environment where all children are accepted and celebrated, where they learn together and from one another.

Education Award
Michael Hohman

The Education Award honors a devoted individual in the field of education whose extraordinary efforts empower students with disabilities to succeed. This year’s recipient is Michael Hohman, teacher at the Ninth Grade Academy in the Rush-Henrietta Central School District.

Mike Hohman’s goal for students is to help them graduate high school and become positive contributors to society in whatever capacity they choose. During his 15-year career as a teacher Mike has worked with over 1,000 students. Sue Wyatt, the parent nominator, commends Mike for being an extraordinary advocate for her son. Mike helps students who are struggling to find glimmers of hope and not give up on education. In one instance, Mike persisted for five years in guiding a student from a kindergarten to a 6th grade reading level and eventual graduation. MCC classes, and employment. In a system that is standards-based, Mike helps students demonstrate that they meet those standards as efficiently and painlessly as possible. This extraordinary teacher has made it his work to see that students do not give up on themselves.
The Founders Award
Deb & Rich Vanderpool

The Founders Award honors a parent or family member of an individual with a disability who exemplifies our founders’ commitment to improving the quality of life for individuals with disabilities. This year, two parents are honored: Deb and Rich Vanderpool, or “Team Vanderpool” as their friend and nominator, Lynda Mueller, calls them.

Deb and Rich are the parents of Jon, age 26, and Jason, age 23, who both have Sanfilippo syndrome, a genetic disorder which manifests itself when children are young, and eventually causes significant neurological symptoms, deterioration of motor skills, and intellectual decline. The Vanderpools are active in local and national organizations related to Sanfilippo syndrome and developmental disabilities. As members of the National MPS* Society, the Vanderpools travel around the country to attend meetings and to support other families. Lynda commends Deb and Rich for supporting families who struggle to access experimental treatments and for “the tireless fight” that they wage against drug companies that deny research funding. These remarkable parents have enrolled their sons in numerous research studies which may lead to a cure, all the while knowing that Jon and Jason may not be the ones who benefit from that research.

The Youth Award
“CJ” Clemont

The Youth Award honors an individual, age 21 or younger, whose efforts make a positive difference in the lives of individuals with disabilities. This year’s winner is Curtis John “CJ” Clemont.

At only ten years of age, CJ has already made significant contributions for autism-related programs, inspired by his younger brother, Jack – whose nickname is “Jackpot.” This past year, CJ raised more than $8,000 to benefit Camp Puzzle Peace’s Family Camp program. The camp is located in the Adirondacks and offers educational and recreational activities for children on the Autism spectrum and their families. CJ said, “We went to Camp Puzzle Peace the first year, and I’ve never seen my brother smile so much, and I just wanted to see him smile more and other people smile more.” CJ was nominated by Joshua Fidler, the 2011 Youth Award winner. Joshua and CJ both spoke at an autism conference a year ago, describing the rewards and challenges of having a sibling with autism. Joshua observed that although CJ was just 9 years old, he “spoke eloquently about his own fears and concerns in front of a large audience of parents and professionals and truly moved everyone.”

Congratulations to all of our Community Award Winners!

The Outstanding Community Partner Award
Walter Parkes

The Outstanding Community Partner Award honors an individual or organization who has demonstrated generous and sustained support of the work of organizations like LDA Life and Learning Services and The Advocacy Center. The 2014 recipient of this award is Walter Parkes, Chairman of the Board of O’Connell Electric Company.

O’Connell Electric is one of the largest, highest ranked electrical contractors in the country. In addition to his significant business presence, Walter is highly active in supporting the health and well-being of the community. He is a valued member of the LDA Life and Learning Services Partners in Learning Society. Walter and his wife, Carmina, and their family have established The Mary M. Parkes Center for Asthma, Allergy, and Pulmonary Care, affiliated with the University of Rochester Medical Center, in honor of their daughter, Mary M. Parkes. The Walter and Carmina Parkes Family Foundation provides supplemental aid to charitable organizations throughout the communities where O’Connell employees work and live. He also serves as a board member of the Pluta Cancer Center. In recognition of his numerous outstanding business achievements and contributions to the community, Walter is an inductee in the Rochester Business Hall of Fame. Additional honors include The National Electrical Contractors Association prestigious James H. McGraw award; the Electrical Contracting Foundation Wendt award for exemplary leadership and service; and the Rochester Builders Exchange’s Lifetime Achievement Award.
One of Pat's dreams is to work in a coaching or managerial capacity for a college or NFL team. A linebacker and wide receiver on Gates-Chili High School’s scout team, Pat’s main responsibility is to prepare the team starters by engaging in practice games. He plays defense and special teams in scrimmages. Pat goes to the weight room every day and is never late for practice. Pat may follow in his dad’s footsteps: Lee Staley is currently a football coach for Caledonia-Mumford H.S. and formerly a coach at St. John Fisher College.

Another area of interest for this fit young man who loves warm weather is landscaping. Pat hopes to turn his summer lawn care experience into his own business. His mother, Dee Staley, describes his first customer. “She is a friend who also understands a fair amount about autism. She copied a map of her property, highlighting certain areas that needed particular care, and included notes and symbols showing conditions of the yard. She understood that he needed certain accommodations to be successful. Pat does great with visual and step-by-step instructions.” The only problem Pat faced was that he didn’t have sufficient lawn equipment to do the job thoroughly. The Creating a Life series provides a funding opportunity for graduates to initiate a plan, so Pat used the funds to purchase battery operated, eco-friendly, lawn equipment. Dee notes that all the tools include safety features. “We would not have been able to purchase all this equipment without the grant.”

Patrick is an active and valued community member. Leadership and dedication to youth are repeated themes in Pat’s substantial volunteer work. For his Eagle Scout project, Pat built a preschool stage for the Gates Recreation Center, complete with colorful carpeting to appeal to the youngsters. Now, Pat helps other prospective Eagle Scouts with their projects. At Community Christian Church in Chili, he is a Sunday school helper who keeps youngsters on track during activities. He is a volunteer in South West Ecumenical Ministry (SWEM), in which he packages food monthly for distribution to community members in need.

Pat is taking Peer Leadership this year, a course offered by Gates-Chili to encourage team leadership, community service, and volunteerism. He was among the group of peer mentors who provided tips to the incoming 9th grade students as they negotiated their way around a new school building and high school life.

So what will life after high school look like? Pat is discovering all his options. He is exploring the post-secondary programs offered by Roberts Wesleyan College, among others. He is considering taking a coaching certification class next summer and then perhaps applying for a coaching internship at a local college. He is currently working on developing a website for his lawn care business. He would love to visit big cities like Seattle, St. Louis, Chicago, and New York and while there, catch football or baseball pros in action. Closer to home, he wants to learn to drive, like his sister, Leah, a student at SUNY Brockport.

“This year and next year will be pivotal in Patrick’s articulating what he wants to do in the future and making strides toward those goals,” says Dee.

Armed with football gear, lawn equipment, numerous talents, and a great attitude, it seems that Patrick is well on his way.
**The Advocacy Center Upcoming Events & Workshops**

REGISTRATION IS REQUIRED FOR ALL WORKSHOPS

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**The Inside Scoop: Meeting Children's Medical Needs in the Home, School, and Community**

A Three-Part Series ideal for Parents and Professionals

Wednesdays, 9:30 am to 12:30 pm at
The Advocacy Center, 590 South Avenue, Rochester, NY 14620

Develop your knowledge and skills to effectively navigate the health, education and disability service systems.

- **October 15** - Building a Supportive Team
- **October 22** - Building Effective Relationships: Parents and Medical Professionals Working Together
- **October 29** - Bridging the Gap: How to Access Information and Resources

REGISTRATION IS REQUIRED. To register, please email: registration@advocacycenter.com or phone (585) 546-1700 ext. 256. Workshop series is FREE to family members and professionals

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**CSE Overview**

The Committee on Special Education (CSE) is responsible for developing a child’s Individualized Education Program (IEP) through a process which involves the student and parents. This workshop will explain the purpose of the CSE, the required members, and the parents’ role on the committee.

- **November 4**

**IEP Essentials**

This workshop will give parents an overview on how to participate on the Individual Education Program (IEP) team by understanding what must be on an IEP in order to make it an effective working document.

- **October 21** • **November 18**

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**Creating Connections & Demystifying Disabilities**

**Creating Connections in Schools:**

Our school program is a student-focused presentation which supports both Positive Behavior Interventions and Supports and the Dignity for All Students Act (DASA). Content can be delivered to any grade level and tailored to meet the needs of the classroom. A large-group presentation can also be arranged if your school desires.

- **October 21**

**Creating Connections in Workplaces & Organizations:**

Nearly 1 in 5 Americans have some form of disability. Individuals with disabilities, their families, and their friends are more likely to shop at, dine at, or engage the services of businesses that are accessible and inclusive. In addition, businesses that are flexible and open to employing the talents of all individuals promote a workplace culture of collaboration and success.

Our programs are designed to contribute to increased sensitivity and acceptance of diversity within our schools, workplaces, and communities.

To arrange for a workshop, contact Courtney Dolan, LMSW, Public Education Coordinator, at 585-546-1700, Ext. 267.

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For current news on the merger of The Advocacy Center and LDA Life and Learning Services, please visit our website: http://advocacycenter.com/news-about-the-merger
Giving to Others

Individuals with disabilities give back to their communities in many ways and, just like all volunteers, enjoy the opportunity to explore interests, cultivate friendships, experience the satisfaction of a job well done, and discover the joy of giving.

Benefits of Volunteering

Social Inclusion, Community Membership and Friendship

- Given the social isolation of many people with developmental disabilities, volunteering is important and one of the most useful avenues for really getting to know other community members.
- While efforts to promote volunteerism should never displace finding jobs and increasing the income of people with disabilities, many people with limitations in their abilities and vocational opportunities will not have the chance to befriend others through work, volunteering can provide powerful alternatives.
- Relationship opportunities are maximized when community members get to know one person with disabilities at a time. Programs congregating individuals with developmental disabilities all at the same time will not provide the opportunity for real social inclusion. Substituting congregated community “volunteering” for a congregated day habilitation program will not promote community belonging.

Developing Marketable Skills and Job Opportunities

Volunteering provides many opportunities to learn and to practice skills that can be useful in paid employment. Of course, one of the things to beware of is that volunteering cannot substitute for work that should otherwise be paid. A useful gauge is whether non-disabled community members volunteer in that particular way; if they do, then it is also a legitimate volunteering opportunity for people with disabilities.

Networking

A fact of life is that “who you know” affects most everything. For instance, about 70% of all jobs are obtained through personal contacts.

Status and Reputation

In any city or town in the country, examine the lives of the people considered the leading citizens. Almost invariably, everyone is involved in some form of volunteering. For individuals who have historically been in the most socially devalued roles, their volunteering can serve to shift their own view of themselves, as well as their community’s and the entire cultural view of people with disabilities.


The Link Between Volunteerism and Competitive Employment

New research released by CNCS (Corporation for National and Community Service) in June 2013: Key findings on the connection between volunteering and employment include the following:

- Volunteers have a 27 percent higher likelihood of finding a job after being out of work than non-volunteers;
- Volunteers without a high school diploma have a 51 percent higher likelihood of finding employment;
- Volunteers living in rural areas have a 55 percent higher likelihood of finding employment.

CNCS also found that volunteering is associated with an increased likelihood of finding employment for all volunteers regardless of a person’s gender, age, ethnicity, geographical area, or the job market conditions. (Spera et al, 2013).

According to CNCS, volunteering can help people find employment because:

- Volunteering increases an individual’s networks and connections;
- Volunteering increases an individual’s experience or useful education, skills, and training; and,
- Volunteering helps to create a positive impression in a competitive job market.

From Pathway to Employment for Youth with Disabilities, Corporation for National and Community Service, Office of Disability Employment Policy http://www.nationalservice.gov/about/pathway-to-employment
The Advocacy Center’s Laura Arrington, Parent Center Coordinator, and Courtney Dolan, Public Education Coordinator, recently visited Core Athletix to learn more about Rubies. Rubies is an inclusive cheer team coordinated by Core Athletix. Rubies work on fine and gross motor skills, self-esteem, team interactions and language skills through activities aimed at developing a comprehensive cheer routine.

Coach Taylor Coffman describes why he started Rubies. “When I was a coach in Birmingham, Alabama, I started a special needs cheer team and I wanted to continue that here in Rochester. I spoke with Rob Ulrich, Core Athletix owner, and he was very supportive of the idea. I really wanted to create an opportunity for all kids to be included in their community.”

Meet a few parents and participants

Jessica O’Donnell travels from Syracuse to have her son, Jaylin, participate in Rubies. She always wanted Jaylin to try cheerleading and when she heard Core Athletix was starting a team, she was willing to travel. Jaylin gave a statement through facilitated communication “It’s a fun cheer team. I like my coaches and my team mates. Coach Taylor is a cool guy.”

Jamie Lynn Turner’s daughter, Isla, started stunting the first day and was a little nervous going up so high, but she enjoyed it. Isla went to school the next day and told her teachers and friends all about cheerleading. She loves going every week and it was very important to her that she got a bow like all the other kids. She loved the day when Coach Taylor gave her a cheer bow! Jamie says Core helps build Isla’s confidence.

Julie Buick discovered that Rubies was not just for girls. She and her sons, Billy and Bobby, felt welcomed from the minute they walked in the door. One of the teachers, Amy Leo, came right over and wanted to get to know them and what she could do to support the boys and make them feel good. It’s giving the person something they need.” Meet Eileen at: http://www.advocacycenter.com/news/2014/07/07/one-family-s-legacy-of-love

Joe Jackson volunteers at Warsaw High School, Wyoming County Community Hospital, Wyoming County YMCA, Wyoming County Dog Shelter, and at the Church of Jesus Christ of Latter Day Saints in Warsaw, among others.

Nick Schaertel volunteers at the Eastside YMCA, Rochester Broadway Theater League, and Holy Trinity Church in Webster.

Patrick Staley volunteers for Eagle Scouts, SWEM (South West Ecumenical Ministry), and Community Christian Church in Chili.

Rachael Yingling volunteers at Foodlink, the Episcopal Home, and Hope Lodge, through WOW (Without Walls), coordinated by Lifetime Assistance.

Success stories continue to roll in from other parents and participants. Flo Englerth read the positive reviews about Rubies, and needed to check it out herself. She was worried that her daughter, Sabrina, would be put into a situation where she might feel bad about herself because she was unable to do something. Her fears were quickly gone when she walked in. “Coach Taylor immediately put me at ease. He has high expectations for all the kids but he knows when to push and when not to push. He is always working to make each kid successful.” Sabrina feels included and part of the Core Athletix family!

Practices are Sundays from 1:00 to 2:00 pm at Core Athletix facility, 1344 University Ave. Suite #5000, Rochester, NY 14607. Participation in Rubies is free of charge. Currently, Rubies consists of 24 athletes ranging in age from 5-18; the team is currently accepting new participants. Contact: Core Athletix, (585) 244-2496 or visit the website: http://www.coreathletix.com
Partners In Policymaking News

Interested in influencing policy development and systems change advocacy? NYS Partners in Policymaking may be for you! The innovative leadership development training is primarily delivered on-line using interactive web-based tools. New changes in 2015 allow for more comprehensive, cohesive curriculum delivery in a spring and fall 2015 session. Applications will be available after November 1, 2014 at www.nyspip.org/

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