# **BAILEY'S TEAM for AUTISM**

Raising funds and awareness in support of individuals living with autism spectrum disorders and their families, with a focus on research, education and programming.

Bailey's Team is helping to put the pieces together!

SPRING 2019 Newsletter – Prepared by Sammi Robertson

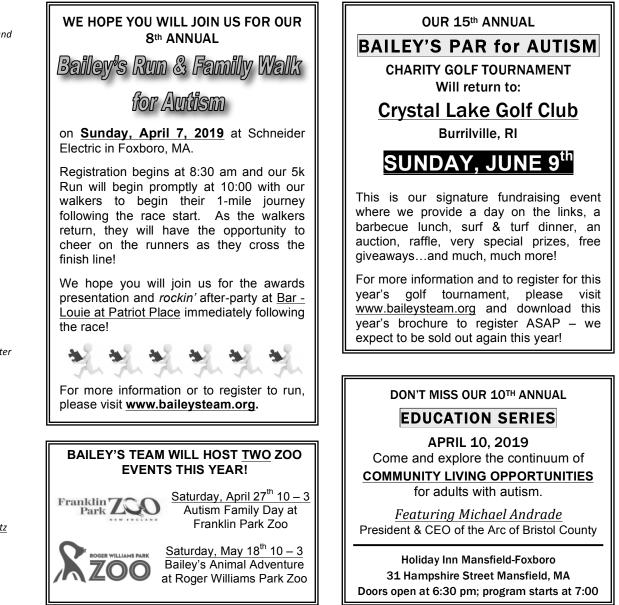


Dear Friend,

Welcome to the twenty-first edition of our BAILEY'S TEAM for AUTISM newsletter! We have included updates on our fundraising success, our life with Bailey... his achievements and challenges, our upcoming event schedule, as well as other plans for the future. We thank you for your continued interest and support and hope you enjoy our newsletter.

# BAILEY'S TEAM FOR AUTISM CELEBRATES TEN YEARS INCORPORATED!

### ...AND FUNDS 13 PROPOSALS IN MARCH OF 2019!



For more information about BAILEY'S TEAM for AUTISM, please visit www.baileysteam.org

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### A Message from the President FAMILY UPDATE

Dear Friends,

We do hope that you are finding our newsletter to be informative, whether on your own journey with autism, supporting a friend who has a loved one with a developmental disability, or as a caring supporter of Bailey's Team and the greater autism community. We began this newsletter as a way to keep people informed about what we are doing as an organization, as a family and as a community. As Bailey heads toward adulthood, the details of our stories will change as the challenges change with each year that passes. If you have any questions about stories printed, or are in search of support, please feel free to contact us via email or by phone. It is our desire to try to help one family at a time, while also supporting organizations whose mission it is to support those living with autism spectrum disorders.

It was 10 years ago that we distributed our first newsletter after having sent letters to our patrons since 2001. Our first newsletter edition was in the spring of 2009 and spoke of our accomplishments and giving with a family letter such as this and a few pictures from our fifth annual golf tournament. We offered a few upcoming events but had not yet started our run, education series or zoo events. We recently celebrated 10 years as an organization, yet it seems like only yesterday that I was boasting about reaching our 5-year mark citing our accomplishments.

Bailey is now 19 years old and doing better than ever. His language continues to emerge and I find myself speaking to him and often getting a sometimes limited, yet meaningful response. Since last spring, we have secured that he is, in fact, eligible for ongoing adult services (which was really not in question, however, a required process). He is also now receiving social security, which supports his community outing spending and support staff, among other necessities. We still have yet to obtain legal guardianship, which we are pursuing finally in the months ahead.

Our latest experience on our journey supporting an adult with autism has to do yet again with Bailey's difficulty self-regulating his behavior when the Internet is not working. One evening in December, while playing on the computer, the Internet went down and Bailey's voice grew loud asking for help. As a result, I told him I would fix the problem; however, was not able to do so fast enough. Bailey was not able to remain calm and after about 15 minutes of our failure to restore the Internet, Bailey became aggressive toward me (mom) and his brother, Spencer, came to my aid in an effort to restrain him. Our own frustrations and upset made it difficult to de-escalate matters. Unfortunately this went on for a bit and when Doug came upon the situation, it was his support that helped contain Bailey's frustration and the event quickly ended. Days later, the Department of Children and Families (DCF) reached out to us as it had been reported that Spencer was not safe in our home due to Bailey's outburst(s). When DCF calls, their job it to investigate a potential situation, in this case Spencer's safety was in question since he is not yet 18 and still a minor. We do our best to keep everyone safe, but at times it feels as though it is out of our hands. Although we are all at risk at one time or another due to Bailey's autism and the random occurrence of his inability to self-regulate, one can't help but feel ashamed when receiving a call like this. Thus far, there has been no formal action taken or follow up; although we are now "in the system." Maybe a good place to be... yet this was just another incident to put on the list that comes with raising Bailey.

A happier experience of late was travelling as a family with Lindsay, Brent and the girls to Disney World in January. It took a lot of preparation relative to our flight, our accommodations, our schedule and conveying our plans to Bailey, but we have mastered this particular trip and were able to enjoy four nights away and three full days at the parks! Between our handicap pass, fast passes, the meal plan, and numerous reservations, our days and nights were not our own, but wonderful at that! It was priceless to get to experience Disney for the first time with Georgie and Bernadette!

Bailey's school program continues to serve him well as he travels throughout the community daily. He attends social skills groups, different job sites and now participates in a program at Bridgewater State University. So yes, Bailey now "goes to college" like Rachel. He happily tells you when asked that he goes to Bridgewater to College. We are slowly preparing him for Spencer's departure in August, which we anticipate will be a difficult transition for all of us – especially Bailey. He relies a lot on Spencer for support and often checks in with him throughout the day. It will be hard for Spencer too as he continues to love and care for his brother tremendously. Another difficult transition will be when Rachel and Jeff move back in July. Yes we will have a full house until Spencer leaves, and Bailey will simply have to get used to the chaos! Easier said than done!



Bailey & Lindsay (& Mario) at Chatham Bars Inn



Best friends Elijah & Bailey at Bailey's 19<sup>th</sup> birthday party



Bailey at a workshop making a Christmas gift for his nieces



Bailey happy to be at Disney on Ice!



Rachel, Bailey & Spencer at Disney World

#### FAMILY UPDATE

[Continued from page 2]

Rachel will graduate from SNHU in a few short months on May 11<sup>th</sup>... ready or not world, here she comes! Rachel is also celebrating her engagement to Jeff Hangen, her boyfriend of three years! They are very happy and are looking ahead to their nuptials in the fall of 2021 after he graduates from law school and takes the Bar exam.

Spencer is also looking ahead as he will graduate from North Attleboro High School on June 7<sup>th</sup> and following what we hope will be a work-filled summer, he will travel to Washington DC to begin his college adventure at American University. He is very excited to embark on the next part of his journey, as he will study film along with business and entertainment; and we are all excited to visit him in our nation's capitol!

As I mentioned previously, Lindsay, Brent, Georgie and Bernadette joined us for our trip to Disney World in mid January! It was nice to spend that time with them, as our visits to Pennsylvania are too few and far between! The girls are now 7 and soon to be 5 and keeping busy with many extracurricular activities including art, yoga and tennis to name a few.







Auntie Rachel & Georgie at breakfast at WDW Auntie Rachel, Uncle-Bailey & Bernadette Bernadette & Georgie at home

Doug and I are doing well as we are all adjusting to the loss of Doug's father, Andy Robertson. He will forever be in our thoughts and we thank you all for your kindness and donations in his honor.

As always, we thank you for your ongoing support, as we wouldn't survive this journey without you!

- Sammi Robertson

### TRIBUTE CARDS

In 2008, we introduced our Tribute Card Program, providing individuals with the opportunity to make a donation in honor of a special someone, in celebration of a special occasion or in memory of a loved one. To date, this initiative has raised over \$13,600 for Bailey's Team.

If you would like to make a donation in honor or in memory of someone special, please visit <u>www.baileysteam.org</u> and download our tribute form for more information.

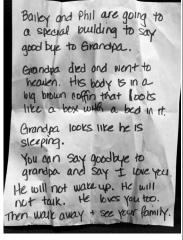


### BAILEY'S TEAM for AUTISM 2018 ANNUAL REPORT

2018 ANNUAL REPORT		
TOTAL FUNDS RAISED NET OF EVENT EXPENSES: Bailey's PAR / Golf Tournament Bailey's Run for Autism Wine & Spirits Tasting Event Major Gifts Annual Campaign Third Party Fundraising Tribute Program Bailey's Team Marketplace (Jewelry & Ties) * Marketplace deficit is due to inventory investment.	ິ	2,900 26,700 11,300 10,800 10,500 3,700 1,100 300 1,500)
CARRYFORWARD FUNDS ALLOCATED FOR FUNDING:	\$	4,600
TOTAL PROGRAM FUNDING AWARDED TO DATE:The Miracle Project – New EnglandSouth Coast Education CollaborativeAmego, Inc. – Fun in Learning Play SpaceArc of Bristol County – Education & AdvocacyArc of Massachusetts – Operation House CallBailey's Animal Adventure – Family EventBrown Center Study for Children at RiskAutism Families CONNECTicut – Recreation Prog.MGH Lurie Center – Consultation & Ed. ServicesBradley Hospital – Healing Arts ProgramFull Spectrum Football – Autism Soccer ProgramLeague School – iPads for Residential ProgramBailey's Team Education SeriesBailey's Team – Franklin Park Zoo EventArc of Quinebaug Valley, Inc.–Supplies/Equipment	\$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$	5,700 6,000 5,700 5,000 5,000 5,000 5,000 4,000 3,800 3,000 3,000 3,000 1,500 1,500 700
FUNDS SET ASIDE FOR SPONSORSHIPS: Autism Project - Imagine Walk Arc of South Norfolk – Gala Sponsorship Autism Society of RI / Groden Network Walk	\$	5,500 2,500 2,500 500
FUNDS SET ASIDE FOR FUTURE PROGRAMMING:	\$	0
TOTAL FUNDS AWARDED / SET ASIDE:	\$6	51,200
PERCENT (%) OF GIVING:		90%
REMAINING FUNDS FOR 2018 OPER. BUDGET: (10%)	\$	6,300

# An Important Tool to Support People with Autism to Understand Death & Tradition

At the time that Bailey's grandfather died, we weren't sure how to explain to him both about Grandpa's death and what came next. After consulting with other moms and my friend. Joanne Quinn of the Autism Project, I opted to write this note for Bailey to read and process what was next as we wanted to bring him to the wake. We had been telling him that Grandpa was in heaven, but he was about to see him in a coffin. This note helped him understand with the help of Bailey's aide, Phil; so we wanted to share it with other families.



# IN MEMORY OF ANDREW E. Q. ROBERTSON, JR.



Early morning, February 7<sup>th</sup>, Andy Robertson passed away after a long battle with both Emphysema and COPD. He was the Patriarch of the Robertson clan surviving both his parents and siblings and was a proud husband, father, grandfather and great-grandfather. He was Bailey's grandfather and as we have told Bailey, he is definitely in heaven and will be missed by all who knew him.

Doug's brother Scott delivered a very special eulogy in memory of their father and shared his thoughts with us so that we could share with all of Bailey's Team how much Andy meant to us.

"When I think of my dad, I think of the smile.... Not only the smile he always had on his face, but also the smiles he brought to other people's faces. The smiles he gave to people so often and so generously..."

Andy was born in 1935 and was the youngest of 3 children. It was said while looking at pictures of Andy as a child, you could see a sparkle in his eye and when he would tell stories about his childhood they were fun, adventurous and sometimes dangerous, which most likely came with that sparkle.

At nineteen year's old, Andy joined the army. The day was June 14<sup>th</sup>, Flag Day. He was in the army for 2 years and left the army also on June 14<sup>th</sup>! It was for this reason that we believe he loved Flag Day. In fact, every year, his children, his grandchildren and good friends would call him to wish him a happy Flag Day... it was the family joke and every year the contest was who would be the first to call Grandpa!

Andy liked people, and would to talk to anyone any time. In just the last few years, he got an iPad and it became his window to the outside world as he began to slow down. He would sit in his living room and go on the Internet to read and learn. He would become frustrated if his iPad wasn't working and when troubleshooting, we would learn that he had 25 or 30 Internet pages open. They were.... National Geographic, John Wayne, Marsupials, Nobel Prize winners, how old is Nancy Pelosi, list of cathedrals in Russia, how to relieve pain in your joints, Roger Williams, etc. You can tell that he had a thirst for knowledge and apparently a touch of ADD.

BUT... the window he always had open on his iPad was the lottery. He played faithfully. He played Mega millions and Powerball every week. He would say to all of us... "You won't have to go to work tomorrow, I played Powerball, and you're all set." He said he would take care of everyone so they didn't have to work anymore... the best part was that he believed he was going to win.

Many people said that Andy was very funny, often making them laugh. He was kind and loving and very affectionate! He would always end a visit with a handshake or a loving hug, followed by his signature "**Love Ya.**"

Toward the end of his years working as a welder, a maintenance manager, fixture maker and finally, a bus driver; Andy spent more time doing what he loved, fishing; and it was his dear friend, Randy, who would give him many more years of fishing than he would have had without him. Their tradition as they set out of the slip and into the bay, would be to play *What a Wonderful World* by Louie Armstrong and he would sing along. He was one of the good guys, one of the best, funny, witty and kind... and lived his life happily singing "What a Wonderful World," making the world wonderful for the rest of us.

# **BAILEY'S TEAM SUPPORTS OPERATION HOUSECALL**

A key value that Bailey's Team offers to our supporters and donors is our Board's critical review of funding proposals submitted by agencies serving individuals on the autism spectrum. The Board's multi-disciplinary perspective, as first responders, researchers, educators, program administrators, therapists, and parents, enables a comprehensive and balanced review of each submitted proposal. This measured assessment ensures that the funds received from individual donations and our events' successes are directed to programs that deliver impactful outcomes. The Board considers this review process their most important responsibility to both our donors and the autism community.

*Operation House Call* is a perfect example of one of the most impactful programs to which Bailey's Team has directed funds. This program, which the *Arc of Massachusetts* operates, brings medical and nursing students into the homes of individuals with autism. The objective is to cultivate within these future clinicians an awareness, patience, sensitivity, and a passion to analyze and understand the dynamic of the often-idiosyncratic complexity of health issues that an individual with autism presents. To augment this real-life learning experience, the medical and nursing students also attend a lecture given by a parent instructor who has a child with autism or intellectual and developmental disability followed by a open "Q & A" session with a co-teacher on the autism spectrum or having an intellectual and developmental disability.

Unique to the Operation House Call program, the participating medical and nursing schools require their students to write a self-reflective essay on the personal value of this learning experience. Participating schools include UMass Medical School, Boston University School of Medicine, Tufts School of Medicine, Simmons College of Nursing and Health Science, and the Yale School of Nursing.

Bailey's Team for Autism is proud to provide support to this creative and valuable initiative that contributes to the medical education of these future caregivers of our loved ones with autism.

# **2018 FUNDING HIGHLIGHTS**

**THE MIRACLE PROJECT – NEW ENGLAND:** \$6,000 to support the cost of a Miracle Project expressive arts camp to be held in June for individuals with autism and their peers between their school and extended school year (summer) programs. The funds will support the cost of training, materials and program execution.

**South Coast Education Collaborative:** \$5,700 to support a Coding and Developmental Employment Opportunities Project. This initiative is well underway, and Bailey's Team's contribution will be allocated to the equipment needed to help sustain the project.

**<u>AMEGO, INC.</u>**: \$5,000 to support the cost of a new "Fun in Learning" outdoor play space. Funds will be used to purchase safety materials and flooring in addition to a fence to secure the space and other play equipment to enable teaching of foundational social skills to promote natural appropriate play for children and their peers.

**ARC OF BRISTOL COUNTY:** \$5,000 to fund a program to teach and empower families to advocate for their children with autism and to obtain services and supports to ensure their educational success – with a focus on important school-age transition years.

**ARC OF MASSACHUSETTS – OPERATION HOUSECALL:** \$5,000 to fund a home-based program teaching young medical professionals essential skills to better treat people with intellectual and developmental disabilities including autism.

**BAILEY'S ANIMAL ADVENTURE:** \$5,000 to fund a family event at Roger Williams Park Zoo for individuals of all abilities to participate in a welcoming and safe environment with their peers – with and without similar challenges.

**BROWN CENTER STUDY FOR CHILDREN AT RISK:** \$4,000 to support the cost of a study seeking to define the neurocognitive profile of depression in adolescents with autism to improve diagnosis.

**AUTISM FAMILIES CONNECTICUT:** \$3,800 to fund a recreational program serving children with autism between the ages of 3 and 13 called "Playing on the Spectrum." This program was developed to enable children on the autism spectrum to participate in their own sensory-sensitive form of extra-curricular activities on the weekend.

**MGH LURIE CENTER:** \$3,500 to help families' access autism consultation and education services. These services are provided to families who might not otherwise be able to support the cost of these services, but require assistance at IEP meetings, negotiating at-home support or simply seeking guidance about how to care for their loved one on the autism spectrum.

**BRADLEY HOSPITAL:** \$3,000 to fund the cost of one artist contracted to participate in a "Healing Arts" program provided to hospital-based patients on the autism spectrum. It is believed that expressive arts programming implemented in conjunction with psychiatric services improve the outcomes for patients' success.

**FULL SPECTRUM FOOTBALL:** \$3,000 to support the cost of a new Autism Soccer program. This pilot program aims to provide a youth sports program with unique components to accommodate and benefit children with autism and their caregivers so that the positive outcomes associated with sports are more accessible to this population. The goal is to serve children with autism regardless of verbal ability, previous experience, physical fitness level, sensory profile, accommodations needed, etc.

**LEAGUE SCHOOL OF GREATER BOSTON:** \$3,000 to support the purchase of five iPads and cases to serve individuals in the school's residential program providing access to learning through technology beyond classroom hours.

**BAILEY'S TEAM EDUCATION SERIES:** \$1,500 to fund one individual program featuring Michael Andrade, President & CEO of the Arc of Bristol County, who will speak about the continuum of living opportunities for individuals with autism approaching adulthood.

**BAILEY'S TEAM FRANKLIN PARK ZOO EVENT:** \$1,500 to fund an Autism Family Day providing free entrance to one caregiver/family member for every person with autism who attends this event. The Franklin Park Zoo will support the cost for each individual on the spectrum and games and other special activities will be provided. In addition, Bailey's Team will provide a "goody bag" filled with fun items to every family who pre-registers.

**ARC OF QUINEBAUG VALLEY – SUPPLIES FOR AUTISM SERVICES:** \$700 to support the cost of materials for the individuals with autism served to include weighted vests, sensory lights, an audio sedation system and a therapeutic sand tray.

**THE ARC OF SOUTH NORFOLK – GALA SPONSORSHIP:** \$2,500 sponsorship to support the cost of programming for individuals with autism and their families.

**AUTISM PROJECT – IMAGINE WALK & FAMILY FUN DAY:** \$2,500 sponsorship to be allocated to various programs and training for individuals living with autism and their families.

**AUTISM SOCIETY OF RI / GRODEN NETWORK WALK**: \$500 sponsorship to fund programming offered by both the Groden Network and the Autism Society of America – Rhode Island Chapter.

### BAILEY'S TEAM FOR AUTISM CELEBRATES TEN YEARS AT OUR ANNUAL MEETING IN OCTOBER, 2018 AT TAVOLINO'S AT PATRIOT PLACE



Top Row: (L to R) Paul LaCava, Betsy Roche, Dan Joyce, Todd Levine\* & Doug Robertson

<u>Middle Row: (L to R)</u> Amy Laurent, Ruth Hoshino\*, Danielle DesRosiers\*, Amy Tonkonogy, Sheila Burgess, Julie O'Brien\* & Sammi Robertson

Bottom Row: (L to R) Tom Buckley, Beth Jerskey, Keith Duclos & Tony Calcia\*

\* Former Bailey's Team Board Members

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### **KDC CELEBRATES BAILEY'S TEAM**

On February 7<sup>th</sup>, Kennedy Donovan Center (KDC) unveiled a plaque in honor of Bailey's Team for funding their new Applied Behavior Analysis (ABA) program area.



Pictured Left to Right: Simon Welsby, Chief Development Officer at KDC, Sheila Burgess and Tom Buckley, Bailey's Team Board Directors, Courtney Keleher, VP of Children Services at KDC, Gina Shea, ABA Regional Supervisor at KDC & Brian Jadro, Program Director for KDC's ABA Program

#### **2019 UPCOMING EVENTS**

#### **APRIL IS AUTISM AWARENESS MONTH**

APRIL 2	WORLD AUTISM AWARENESS DAY
<u>APRIL 7</u> ₩ 10:00 am	8 <sup>th</sup> Annual BAILEY'S RUN FOR AUTISM & FAMILY WALK FOR AUTISM Schneider Electric - Foxboro, MA Rockin' After-Party Bar Louie at Patriot Place – Foxboro, MA
<u>APRIL 10</u> 7:00 pm	10th Annual EDUCATION SERIES COMMUNITY LIVING OPPORTUNITIES FOR ADULTS WITH AUTISM Come and explore the continuum of living opportunities for individuals with autism approaching adulthood. Presented by Michael Andrade President & CEO – Arc of Bristol County Holiday Inn Mansfield-Foxboro 31 Hampshire Street, Mansfield, MA
<u>APRIL 27</u> 10:00 am	AUTISM FAMILY DAY AT FRANKLIN PARK ZOO Franklin Park Zoo 1 Franklin Park Road Boston, MA
<u>APRIL 28</u> 9:00 am	AUTISM PROJECT IMAGINE WALK Goddard Memorial State Park Warwick, RI
<u>MAY 18</u> 10:00 am	9 <sup>th</sup> Annual BAILEY'S ANIMAL ADVENTURE Roger Williams Park Zoo Providence, RI
<u>JUNE 9</u> 1:00 pm Tee Time	15th Annual BAILEY'S PAR FOR AUTISM   Charity Golf Tournament   Crystal Lake Golf Club   Burrillville, RI
AUGUST 1	ANNUAL CAMPAIGN BEGINS
<u>NOV 1</u> 7:30 pm	11th Annual WINE & SPIRITS TASTING   Skyline at Waterplace   1 Finance Road   Providence, RI
Watch	for our next <u>BAILEY'S TEAM NEWSLETTER</u> to be distributed in October, 2018
For more	information about BAILEY'S TEAM, please visit: www.baileysteam.org

### HOW TO APPLY FOR FUNDING FROM BAILEY'S TEAM

All applications are welcome and are accepted between August 1 and October 15. Please visit our website and click on "Forms" to download our <u>Funding Application</u>. Funding decisions will be made no later than February 10<sup>th</sup>. All awards will be reported in our spring newsletter following our funding cycle.

### **BAILEY'S TEAM BOARD OF DIRECTORS**

**OFFICERS** 

Sammi Robertson President



Amy Laurent Vice President



Dan Joyce Treasurer



Amy Tonkonogy Clerk





Sheila Burgess







DIRECTORS

Beth Jerskey Funding Coordinator









Betsy Roche

IF YOU WOULD LIKE TO SUPPORT BAILEY'S TEAM DONATIONS ARE ALWAYS WELCOME ©				
Name				
Address:				
Phone:Email:	City	State	Zip	
Enclosed is my donation in the amount of \$ Check #				
Credit Card ( <i>Please circle one</i> ): Master	Card / Visa / AMEX /	Discover		
Acct. #	Exp. D	ate:		
Please send this form	n along with your payment to:		. 1	
Bailey's Team for Autism *164 West	tside Avenue * North Attlebor	ro, MA 02760	Thank you!	
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pro.msetsyelisd.www

# Supporting People with Autism and their Families





Bailey's Team for Autism 164 Westside Avenue North Attleboro, MA 02760

At least 1 in 59 children will be diagnosed with autism spectrum disorder this year! Help us put the pieces together by joining our team!