## **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 2020 Newsletter - Prepared by Sammi Robertson



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<u>Irwin & Roberta Chafetz</u> <u>Stephen Shore</u> Dear Friend,

Welcome to the twenty-third 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 FUNDS 14 PROJECTS SERVING FAMILIES IN MASSACHUSETTS, RHODE ISAND, CONNECTICUT, AND NEW HAMPSHIRE!

WE HOPE YOU WILL JOIN US FOR OUR
9th ANNUAL

Bailey's 5k Run &

Family Walk for Autism

on <u>Sunday, March 29, 2020</u> at Schneider Electric in Foxboro, MA.

Registration begins at 8:30 am and our 5k Run will begin promptly at 10:00 with our walkers to begin their 1-mile journey following the race start. As the walkers return, they will have the opportunity to cheer on the runners as they cross the finish line!

We hope you will join us immediately after the run for the awards presentation and rockin' after-party at <u>Bar Louie</u> at Patriot Place in Foxboro!



For more information or to register to run, please visit <a href="www.baileysteam.org">www.baileysteam.org</a>.

# WE HOPE YOU WILL JOIN US FOR OUR ZOO EVENTS THIS YEAR!

Franklin ZCO

Saturday, May 2, 10 – 2 Autism Family Day at Franklin Park Zoo



Saturday, May 9, 10 – 2 Bailey's Animal Adventure at Roger Williams Park Zoo **OUR 16th ANNUAL** 

### **BAILEY'S PAR for AUTISM**

CHARITY GOLF TOURNAMENT

Crystal Lake Golf Club

Burrillville, RI

## SUNDAY, JUNE 14

This is our signature fundraising event where we provide a day on the links, a barbecue lunch, surf & turf dinner, an auction, raffle, very special prizes, free giveaways...and much, much more!

For more information and to register for this event, please visit <a href="www.baileysteam.org">www.baileysteam.org</a> and download this year's brochure to register ASAP – we expect to fill up fast!

## Thursday, October 1, 2020

Celebrating Art & Autism



Jellvfish created by Julia Sposato
Four Points by Sheraton
Norwood, MA

# 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 moves toward adulthood, the details of our stories will change as the challenges will vary with each passing year. 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.

\* \* \*

### Bailey is no longer a teenager! He turned 20 last October and is fast approaching his "transition" age of 22.

Bailey has been doing very well in both his school program and at home. His schedule while at school or "12 +" (which refers to the years after 12<sup>th</sup> grade before transitioning to adult programming at the age of 22 in Massachusetts) consists of community outings and time in the classroom working on a variety of skills. His group travels to a number of work locations such as a shredding program in Mansfield, St. Vincent DePaul's, where they hang and sort clothing, our local food pantry where they sort goods by expiration date and also the local supermarket(s), just to name a few. They also travel to Bridgewater State University (BSU) for learning opportunities and skills training, as well as Fisher College. BSU is a favorite destination as Bailey enjoys his time at lunch in the "Bear's Den" where he can see a lot of students. He also likes to tell us that he goes to college like his brother Spencer!

Although he is just 20, we are approaching a very important transition on our quest for programming that he will require upon his 22<sup>nd</sup> birthday. Unfortunately, there are not a lot of favorable options making it a daunting process. For someone like Bailey, even though his language is very limited, he could certainly thrive in the right program...finding that program is the challenge. He would require a significant amount of support and it would be ideal to have someone who could help facilitate interactions with others both socially and in the workplace. Very few (if any) places of employment offer 1:1 job coaching and Bailey cannot be left on his own, thus limiting his opportunities in a work environment. He is very smart and task-oriented but without the appropriate supports, it is impossible to know how long he could work at a task and if he would stay safe.

Another option for programming would be social skills programming and recreational outings in the community. This, too, would require significant support. And finally, it is important to understand that when an individual transitions into adult programming, these programs are often filled with individuals from ages 22 and higher. Anyone over the age of 22, more specifically older than 40 is not really considered a part of his peer group, and we've not even begun to address their level of function. As we begin to learn about what organizations are out there, it certainly does help to have friends who have already gone through this process and know the pros and cons of available programs. At the end of the day, however, you must consider your own child, his or her strengths and limitations and the end goal should be that they are happy and living a productive life within their community. Sometimes you just wish they could stay in school forever... safe and with those who have cared for him for the past 15 years! It terrifies us to think of where we might be at this time next year and what I will be writing about – the programs we will be considering... and where he will go.

At home Bailey continues to master all levels of video games, primarily Mario Cart and continues to draw his favorite characters. He loves his family and will often interrupt his time on the computer to seek us out for a quick snuggle to "check in" and then return to his gaming. Mom and Dad are his favorites and we often fight over who gets to enjoy his affection first (mom does usually win)!!

He recently finished his Special Olympics Bowling season and although it is not his favorite pastime; he continues to excel... scoring his record string at "165." He is also enrolled in another Miracle Project expressive arts program for 8 weeks at Brown University... adding to his "college experience." Who would have thought Bailey would be "at Brown!" ©



Bailey's Aid, Phil and Bailey wrapping holiday gifts



Bailey proud of his work creating his annual gingerbread house



Bailey and his friend, Meghan at his 20<sup>th</sup> birthday party



Bailey & Mom at our new "Spin for Autism" event



Cousin Ashley & Bailey

#### **FAMILY UPDATE**

[Continued from page 2]

Rachel moved home with her fiancé, Jeff, last May and all I can say is *so far so good!* © She is working full time at Performance Physical Therapy in Smithfield, RI and has made many new friends. She continues to enjoy Bella, her lionhead mix bunny, and has begun to plan for her Sept. 2021 wedding. Jeff is counting the days to his Law School graduation on May 15<sup>th</sup> and then will begin the grueling process of studying for the Massachusetts Bar exam.

Spencer has made his way as a freshman at American University in DC. His first semester was a challenging transition; however, he is now happier than ever having found his community while excelling academically.

Lindsay, Brent, Georgie and Bernadette are doing well as they are all keeping busy with the life of a family with young children. The girls are enrolled in horseback riding, rock climbing, basketball, drawing and lacrosse!



Georgie & Bernadette

Georgie and Bernadette during Mimi's. recent visit to Newtown, PA

Doug and I are doing well and busy with life... work, home, kids, family, friends, Cape Cod and Bailey's Team. We are introducing two new events this year and with that comes the need for more planning and much-appreciated support from all of you!

As always, we thank you for being there... helping us to navigate this journey while also supporting other individuals living with autism and their families!

- 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 \$14,600 for Bailey's Team.

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



# BAILEY'S TEAM for AUTISM 2019 ANNUAL REPORT

TOTAL FUNDS RAISED NET OF EVENT EXPENSES:	\$77,100
Bailey's PAR / Golf Tournament	\$33,700
Wine Tasting Event	\$14,200
Major Gifts	\$12,200
Bailey's Run for Autism	\$ 8,000
Third Party Fundraising	\$ 4,000
Tribute Program	\$ 3,200
Annual Campaign	\$ 3,000
Art Show – Spring 2020 (New Event Preparation)	(\$ 300)
Bailey's Team Marketplace (Jewelry & Ties, etc.)	(\$ 900)
* Marketplace deficit is due to inventory investment.	
CARRYFORWARD FUNDS ALLOCATED FOR FUNDING:	<u>\$ 2,400</u>
TOTAL PROGRAM FUNDING AWARDED TO DATE:	\$69,800
Arc of S. Norfolk – ALEC – 1 <sup>st</sup> Responder Training	\$10,000
People, Inc. – Family Support Center Rec. Club	\$ 6,500
Pathways/J. Arthur Trudeau – Vocational Activities	
Arc of Massachusetts – Operation House Call	\$ 5,000
Autism Project – Parent to Parent Training Series	\$ 5,000
The Miracle Project – New England – Arts Camp	\$ 5,000
Arc of Bristol County – Education & Advocacy	\$ 4,300
Autism Families CONNECTicut – Recreation Prog.	. \$ 4,000
Bailey's Animal Adventure – Zoo Family Event	\$ 4,000
MGH Lurie Center – Consultation & Ed. Services	\$ 4,000
The Groden Network – Coventry School Swingset	\$ 3,400
HMEA – Social Interaction thru Gaming Groups	\$ 3,000
Community Music School – Miracle Project - NH	\$ 2,500
Arc of Eastern CT – Sign Language & Music Prog.	\$ 2,500
Bailey's Team Education Series	\$ 2,500
Community Autism Resources – Parent Retreat	\$ 2,000
Bailey's Team – Franklin Park Zoo Event	\$ 1,000
FUNDS SET ASIDE FOR SPONSORSHIPS:	\$ 2,000
Autism Project - Imagine Walk	\$ 1,000
RICART* – Art Show	\$ 1,000
* Rhode Island Consortium for Autism Research & Treatme	
FUNDS SET ASIDE FOR FUTURE PROGRAMMING:	\$ <u>0</u>
TOTAL FUNDS AWARDED / SET ASIDE:	\$71,800
PERCENT (%) OF GIVING:	90%
	<u>30 70</u>
REMAINING FUNDS FOR 2020 OPER. BUDGET: (10%)	\$ 7,700

# HOW TO APPLY FOR FUNDING FROM BAILEY'S TEAM

All applications are welcome and are accepted between August 1 and October 1. Please visit our website and click on "Forms" to download our Funding Application. 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.

A poem presented at the 12<sup>th</sup> Annual Children's Autism Services Edmonton Conference in Edmonton, Alberta, Canada for a Neurodiversity in Research Panel (January 23, 2020)

#### NeuordiVERSE

Yes, I am autistic,
And I do research and evaluation,
Of programs and of policies so this is quite an invitation...
when I think about the notion of neurodiversity
and assessing whether it is evident in current ASD
interventions and if so... then to what degree?
There is so much to consider; so much that I do see.

I have come to the conclusion that it is very evident in current interventions. Neurodiversity does present in a sense that our "BEST" practices are really a reflection of how starved our current tactics are for some neurodiverse injection. When I look at interventions designed to teach or to support, It's unfortunate, but it's true - so I'm not sorry to report: That a majority of interventions are at best misguided, And at worst, degrading...and they don't even try to hide it.

Let's talk about misguided, because I think it's really common...

Where goals and aims and programming are all what staff and mom want.

It's not to say these humans don't have some good intentions,

But most of you are operating from neurotypical conventions.

From norms and your experience; from what you find effective.

Ironically, its all of you that need to learn to take perspective.

Autistic people have different brains; that are different in their wiring And functioning in a same brain world is challenging and its tiring. The world was made for NT brains and made by them, too The world was made by and for people with brains like you. Too much of current practice aims to make different look the same, But I assure you different things work better for supporting different brains.

Believe it or not, there are different-brained people who have been all the way through school! The neurodiverse and autistic communities should be our greatest tool. They have knowledge, and experience; they share aspects of profiles With students who are in school now; and they know what was worthwhile, And what was damaging to them and what was so much better, So educational practices should be conceptualized together -

If you think things have improved, and there is truly collaboration Between neurotypicals and autistics and all this positive innovation, Then I ask you to consider the last time you, your class, or school or district Sought input about programming directly from autistics. If you don't know or you know it's never, what evidence do you have then, To say that things are much improved from the past and what they have been?

DON'T MISS OUR 11TH ANNUAL

## **EDUCATION SERIES**

**APRIL 15, 2020** 

COMPLIANCE IS NOT THE GOAL:
RETHINKING SUPPORT FOR
AUTISTIC INDIVIDUALS

A positive shift in focus, supporting the development of emotional and energy regulation skills is the goal.

Presented by

Amy Laurent, Ph.D, OTR/L & JÂcqûelyn Fede, Ph.D.

Holiday Inn Mansfield-Foxboro 31 Hampshire Street Mansfield, MA Doors open at 6:30 pm; program starts at 7:00 pm



Level UP!

### **FUNDING HIGHLIGHTS**

<u>ARC OF SOUTH NORFOLK – ALEC</u>: \$10,000 to fund <u>The Autism Law Enforcement Education Coalition</u> (ALEC) to provide training tor First Responders, Public Safety and Emergency Personnel on how to assist individuals with autism in an emergency situation to avoid risk and ensure safety.

<u>PEOPLE, INC.</u>: \$6,500 to support the development of a skills building, social and recreational program providing opportunities for young adults with autism (ages 18 to 30) to participate in community living.

<u>PATHWAYS / J. ARTHUR TRUDEAU</u>: \$5,076 to support the expansion of their vocation activities training including school store skills training as well as the development of breakfast and lunch carts to teach knowledge of sales and item selection.

<u>ARC OF MASSACHUSETTS – OPERATION HOUSECALL</u>: \$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.

**AUTISM PROJECT:** \$5,000 to support the cost of an ongoing Parent-to-Parent training series offered both in English and Spanish. This series provides evidenced-based principles and methods to teach the fundamentals of raising individuals on the autism spectrum and is offered free of charge to parents.

<u>THE MIRACLE PROJECT – NEW ENGLAND</u>: \$5,000 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.

**ARC OF BRISTOL COUNTY:** \$4,325 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.

**AUTISM FAMILIES CONNECTICUT:** \$4,023 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.

**BAILEY'S ANIMAL ADVENTURE:** \$4,000 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.

MGH LURIE CENTER: \$4,000 to help families access autism consultation and education services. These services are provided to families who might not otherwise be able to support their cost, but require assistance at IEP meetings, negotiating at-home support or simply seeking guidance about how to care for their loved one with autism.

**GRODEN NETWORK – GRODEN CENTER SOUTH SCHOOL:** \$3,379 to support the cost of a swingset to be erected in a new fenced in outdoor recreation area at their Groden Center South school location in Coventry, Rhode Island. This area will be fenced in and also include space for soccer and other recreational activities.

ARC OF EASTERN CONNECTICUT (FORMERLY QUINEBAUG VALLEY)— SUPPLIES FOR AUTISM SERVICES: \$2,500 to support the cost of a new program called *Foundations of Communications for the Intellectually and Developmentally Disabled* (IDD) and Autism Community. This program includes teaching sign language and music for individuals with autism to connect with others and to reduce stress in their efforts to communicate.

<u>BAILEY'S TEAM EDUCATION SERIES</u>: \$2,500 to fund one individual program featuring Amy Laurent, Ph.D. OTR/L & <u>JÂcqûelyn</u> Fede, Ph.D., who will speak about... rethinking supports for individuals with autism in order to effectively support them. "Compliance is not the goal."

<u>COMMUNITY MUSIC SCHOOL – THE MIRACLE PROJECT – NEW HAMPSHIRE</u>: \$2,500 to support the cost of a Miracle Project expressive arts program to be held weekly for a period of 14 weeks. This program provides individuals with autism the tools to work on communication, social skills, community, self-awareness and confidence.

**COMMUNITY AUTISM RESOURCES:** \$2,000 to offer scholarship funding for parents who might not be able to attend a Parent Retreat due to cost. This retreat is designed to provide a relaxing, supportive environment for parents and caregivers to reflect on, explore, and share the rewards and challenges of raising a child with ASD.

<u>BAILEY'S TEAM FRANKLIN PARK ZOO EVENT:</u> \$1,000 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.

<u>AUTISM PROJECT – IMAGINE WALK & FAMILY FUN DAY:</u> \$1,000 sponsorship to be allocated to various programs and training for individuals living with autism and their families.

RHODE ISLAND CONSORTIUM FOR AUTISM RESEARCH & TREATMENT (RICART): \$1,000 sponsorship to help cover costs to host their fourth annual Art Show featuring artists on the autism spectrum.

### **ENJOY THESE PICTURES FROM OUR 2019 NOVEMBER WINE TASTING &** 2020 FEBRUARY FUNDING MEETING



Steven & Joan Hartel Cabral with Sammi & Doug Robertson



Chelsea, Heather, Kerry, Sammi & April... the girls from Sundance Clothing in Chatham!



Sisters Kathy Rohrman and Trish Martins, with friend Beth Jerskey, and mom, Mary Lou Anderson



Bailey's Team Board of Directors working hard to determine who to fund!

### **2020 UPCOMING EVENTS**

### APRIL IS AUTISM AWARENESS MONTH

"SPIN OFF" TO SUPPORT BAILEY'S RUN MARCH 1 NEW EVENT!

FOR AUTISM AT REV'D!

Rev'd at Patriot Place - Foxboro, M.

MARCH 29 9th Annual BAILEY'S RUN FOR AUTISM &

10:00 am **FAMILY WALK FOR AUTISM** 

Schneider Electric - Foxboro, MA

Rockin' After-Party

Bar Louie at Patriot Place - Foxboro, MA

**WORLD AUTISM AWARENESS DAY** APRIL 2

APRIL 15 11th Annual EDUCATION SERIES

7:00 pm **COMPLIANCE IS NOT THE GOAL: RETHINKING** 

SUPPORT FOR AUTISTIC INDIVIDUALS

Presented by Amy Laurent, Ph.D, OTR/L &

JÂcqûelyn Fede, Ph.D.

Co-Founders of Autism Level UP! Holiday Inn Mansfield-Foxboro 31 Hampshire Street, Mansfield, MA

**AUTISM PROJECT IMAGINE WALK APRIL 26** 

9:00 am Goddard Memorial State Park

Warwick, RI

MAY 2 2ND Annual AUTISM FAMILY DAY

10:00 am FRANKLIN PARK ZOO

1 Franklin Park Road

Boston, MA

MAY 9 10th Annual BAILEY'S ANIMAL ADVENTURE

Roger Williams Park Zoo 10:00 am

Providence, RI

**JUNE 14** 16th Annual BAILEY'S PAR FOR AUTISM

1:00 pm **Charity Golf Tournament** Tee Time Crystal Lake Golf Club

Burrillville, RI

OCT 1 **CELEBRATING ART & AUTISM** NEW EVENT!

6:30 pm Four Points Sheraton Hotel

Norwood, MA

12th Annual WINE & SPIRITS TASTING NOV 6

7:30 pm Skyline at Waterplace

1 Finance Road

Providence, RI



For more information about BAILEY'S TEAM, please visit:

www.baileysteam.org

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

### **OFFICERS**



Sammi Robertson President



Amy Laurent Vice President



Dan Joyce Treasurer



Beth Jerskey Clerk & Funding Coordinator

### **DIRECTORS**



Tom Buckley



Sheila Burgess



Keith Duclos



Paul LaCava



Sue Linehan



Doug Robertson



Betsy Roche



Amy Tonkonogy

# 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 (Please circle one):	MasterCard	/ Visa / AMEX /	Discover	
Acct. #		Exp. D	ate:	

Please send this form along with your payment to:



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## Supporting People with Autism and their Families



