

10TH ANNIVERSARY REPORT
2008–2018

CENTER FOR AUTISM RESEARCH



LETTER
FROM
THE
DIRECTOR



DEAR FRIENDS,

As CAR prepares to celebrate its 10th anniversary, I find myself reflecting back on why I came to CHOP and the phone call with Susan Levy, MD that sealed the deal. I stood in a space enclosed by plastic tarps blowing in the wind in the middle of my soon-to-be-remodeled kitchen. Susan was outside enjoying the breeze while on vacation. And although we struggled to hear each other over the winds, the critical information got through — CHOP was dead set on creating a world class autism center — a beacon for the field. I leapt at the chance to build something very special and never looked back.

CHOP has provided a caring and vibrant community of colleagues, families, advisors, and supporters, allowing us to build from scratch one of the best known and respected clinical research centers in the world. Our story is one of extraordinary people — gifted scientists, insightful clinicians, and tireless and dedicated families. I am deeply grateful to each of them. Despite headwinds, our story is one of continued growth and accomplishment, coupled with a profound sense of humility for the magnitude of the challenges we all still face.

Looking forward to the next decade, we see a clear path toward achieving our ultimate goal of improved clinical care for individuals with autism: Technology. This report highlights some of the ways CAR is already using technology to enhance both research and clinical care. Through continuous innovation and the power of predictive analytics and big data, we will vastly improve the way clinicians support individuals with autism in a personalized way as their needs change over the course of a lifetime.

I welcome every opportunity to hear your concerns, your ideas, and your own stories. We are in this together, and you can count on our entire institution, and our network of collaborators, to work tirelessly to support your needs. I am confident that our daily work will reveal truths about autism that will enrich the lives of those that we serve.

WITH APPRECIATION,

Robert T. Schultz

Bob Schultz

CAR'S MISSION BY THE NUMBERS

“IF YOU HAVE SEEN ONE PERSON WITH AUTISM, YOU HAVE SEEN ONE PERSON WITH AUTISM.”

Within the autism community, this is a well-known saying that expresses the very reason why autism is considered a “spectrum disorder.” All individuals with autism experience difficulties with social communication and have restricted interests and/or repetitive behaviors that interfere with daily life. But autism looks different in every individual, making it challenging to study and to treat: some individuals have co-occurring intellectual disability, some have learning challenges, and some have savant abilities. Others have seizures, ADHD, or anxiety.

Hundreds of different genetic factors contribute to autism and likely a similar number of environmental factors. Each combines differently to affect an individual diagnosed with ASD. This results in the many different combinations of symptoms – a phenomenon known in the medical world as “heterogeneity.”

The solution to overcoming the challenges of heterogeneity in ASD research is in numbers. Autism studies need to include a substantial amount of data from many individuals all across the spectrum in order to see what patterns emerge. Gathering data and funding studies of the size and scope necessary to account for autism’s myriad expressions has been out of reach — until now.

CAR is at the forefront of developing and applying new technologies to collect more detailed and accurate information than ever before on genomics, brain science, and behavior. CHOP specialists and primary care doctors care for more than 10,000 unique patients with autism each year. By partnering with CHOP patient families and clinicians to collect a detailed understanding of each person’s autism, CAR researchers have a remarkable opportunity to uncover new avenues of research. This depth and breadth of understanding can lead to more effective interventions for each and every person, tailored to their unique combination of characteristics along the spectrum. All have something positive to contribute to their communities, and researchers and clinicians, working in concert with the individuals themselves and their families, must find ways to maximize each person’s potential.

1 IN 40 PEOPLE HAS ASD:

BOYS ARE **3.5** TIMES MORE LIKELY THAN GIRLS TO BE DIAGNOSED.



ANNUALLY CHOP CARES FOR
10,000+ PATIENTS
WITH ASD



RESEARCH THE CAUSES OF ASD IN ORDER TO DEVISE EFFECTIVE, PERSONALIZED TREATMENTS BASED ON GENETIC, NEUROLOGICAL, AND BEHAVIORAL PROFILES

- 10,000+ participants in 200+ CAR studies
- 700+ articles in peer-reviewed journals
- 11 industry partnerships
- 50+ community research partners
- 15 research networks
- 31 collaborating research institutions
- 167 scientific investigators and collaborators at CHOP and UPenn



SUPPORT FAMILIES AND INDIVIDUALS LIVING WITH AUTISM BY PROVIDING EVIDENCE-BASED EDUCATION AND RESOURCES

- 5,000+ parents, professionals, and self-advocates at *Next Steps* workshops
- 1,800+ parents through individual consultations with CAR’s social worker
- 620,000+ visitors to CAR Autism Roadmap™
- 17,000+ subscriptions to CAR’s e-newsletter, *Autism Dispatch*
- 600+ community presentations, including 100+ Distinguished Lecture Series events
- 1,100+ outreach events attended



TRAIN THE NEXT GENERATION OF MASTER CLINICIANS AND RESEARCHERS TO BECOME LEADERS IN THE FIELD AND IMPROVE ACCESS TO CARE

- 200+ graduate students, postdoctoral fellows, and post-baccalaureate researchers across 7 countries
- 720 public school teachers & aides *
- 48 doctors working as autism professionals
- 70 community clinicians
- 20 pediatric residents and 16 general pediatricians in underserved areas
- 24 Autism LEND Fellows
- 36 general psychologists

* in partnership with University of Pennsylvania (UPenn) Psychiatry/Center for Mental Health Policy and Services Research

“AFTER SPENDING LITERALLY THOUSANDS OF HOURS TAKING MY SON TO THERAPY AND DOING TREATMENTS AT HOME, THE IDEA OF BEING ABLE TO TELL IF A THERAPY IS WORKING EARLY IN THE PROCESS IS UNBELIEVABLY EXCITING. IT WILL BE A REAL GAME-CHANGER FOR FAMILIES.”

AMY KRATCHMAN,
CO-CHAIR, AUTISM FAMILY
PARTNERS AT CHOP

TECHNOLOGY ENVISIONS A NEW PATH FOR DIAGNOSIS AND TREATMENT

Two common and persistent questions parents have about a child with autism are: “what will my child’s life look like as he or she grows up?” and “what kinds of educational or lifestyle supports will I need to plan for?”

Since its inception two years ago, CAR’s **Technology and Innovation Lab** has forged a path that will revolutionize psychological assessment and the way doctors measure — and predict — the effectiveness of interventions. The lab has developed and tested a portable system that can flawlessly record and digitize all outward expressions of human behavior. Developed by the lab’s co-founder, **Keith Bartley, MS**, CAR’s “biometric sensor tree,” system can capture more physical and behavioral characteristics than an expert clinician can observe, including tone of voice, facial expression, motion and gestures, heart rate, temperature, and even brain waves when combined with an EEG.

In studies conducted over the past two years, this technology was able to diagnose autism in patients

during a 3-minute conversation with ~90% accuracy. When autism experts were asked to perform the same task, they achieved only 83% accuracy for the 3-minute diagnosis. Less experienced staff were 77% accurate.

The technology also holds promise for assessing the effectiveness of treatments for autism. With pilot trials currently underway, CAR researchers have high hopes this technology will be a more precise and sensitive way to capture subtle changes in behavior than parent report and clinician observation.

After being tested in area schools and camps in 2016, the biometric sensor tree is slated to be deployed later this year in CHOP specialty and primary care practices. When integrated into the **Autism Learning Health System** (see page 22), the sensor tree has the potential to dramatically improve clinicians’ understanding of various profiles of autism, how profiles relate to different underlying causes, and how individuals might respond to different treatments, thus helping families to plan for the future.



CAN YOU HEAR AUTISM?

Researchers at CAR believe that autism has a distinct sound, and they are trying to quantify it. To do so, **Julia Parish-Morris, PhD** and her colleagues are analyzing thousands of audio samples to extract linguistic characteristics or markers that make up a person’s vocal signature. The research is accessible to individuals regardless of their verbal abilities: even babies who are later diagnosed with ASD have been shown to cry and babble differently.

To conduct this research, CAR is making use of the thousands of hours of recorded research evaluations that have taken place at CAR over the years (with parent/participant approval). Researchers are also collecting language at home, in area preschools, and remotely over the phone.

“We hope to correlate linguistic markers with clinical presentations of ASD and biological data, such as genetics and brain imaging,” says Dr. Parish-Morris. She says the team is also interested in exploring linguistic differences between boys and girls, as they have already discovered that girls with ASD have more subtle language differences than boys with ASD.

Early findings have shown that word choice, pause length, disfluency (use of “uh” or “um” to fill pauses), rate of speech, number of words used to convey information, and pitch can be used to differentiate individuals with autism from typically developing peers. Certain linguistic features also correlate with clinical presentation and severity of ASD symptoms. This relationship suggests that looking at an individual’s use of language could help clinicians to tailor personalized approaches to social communication intervention for individuals with ASD.



SUPERCHARGING THE SEARCH FOR THE CAUSES OF AUTISM

50,000 families living with autism are joining together with researchers to discover the genes contributing to autism. Given autism's heterogeneity, team science and collaboration is the only viable path for making rapid progress in autism genetics. CAR is partnering with the **Simons Foundation** and more than 20 other research institutions across the country in this ambitious

endeavor. At the two-year mark, CAR is exceeding expectations for enrollment, on the way to its goal of enrolling 10,000 individuals with ASD in the next 5 years.

At CHOP, CAR is partnering with the **Department of Biomedical and Health Informatics** and the **Division of Developmental and**

Behavioral Pediatrics to integrate genetic data into a biorepository for neurodevelopmental disabilities. As a key component of CHOP's **Autism Learning Health System** (see page 22), the biorepository is a virtual

warehouse combining deidentified genetic data with corresponding medical, developmental, and behavioral information. This information-rich biorepository will accelerate research on the causal mechanisms of autism as well as translational research to develop more effective treatments.

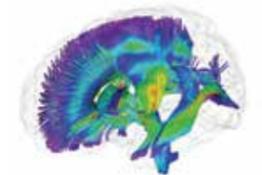
Translational research is always the goal. In 2017, CAR-led research on 22q11.2 Deletion/Duplication Syndrome, a genetic syndrome shared by many individuals with ASD, yielded new screening recommendations for patients. Other genetic research led to a clinical trial for a medicine targeting the metabotropic glutamate receptors (mGluRs), which influence learning, memory, and anxiety. Currently, researchers are using mouse models to explore other medications that could improve social communication. While much research is still needed, CAR is focused on translating its genetic findings into major advances in diagnosis and treatment for individuals with ASD.



INCLUSIVE IMAGING

Timothy Roberts, PhD is using MEG imaging to study auditory processing in non- and minimally-verbal children with ASD. In 2010, Dr. Roberts and his team discovered that verbal children with ASD process sounds a fraction of a second slower than their typically developing peers, causing communication delays. The group is now determining if diminished language ability correlates with increased timing lags.

"Including the entire spectrum of autism ability and disability in research is important so that tailored treatments are developed for all individuals with ASD," says Dr. Roberts. His team creates a unique behavioral plan for each participant and collaborates with other researchers throughout the country to share their strategies.



BRAIN POWER

Juhi Pandey, PhD has a hard time believing that the first children CAR enrolled in the Infant Brain Imaging Study (IBIS) are now transitioning to middle school. For ten years, this study has enrolled infant siblings of children diagnosed with autism to study their brains while monitoring their development. Almost 1,200 families have participated, and 120 children have been diagnosed with ASD. According to Dr. Pandey, "The wealth of brain and behavior data from this invaluable cohort has provided incredible insight into the first emerging biological signs of ASD."

This year's IBIS findings have been particularly exceptional. Using magnetic resonance imaging (MRI) from 6 and 12 month-olds with an older sibling with autism, CAR researchers and their IBIS network colleagues found a brain biomarker that could help to identify children with ASD in infancy. Given that autism is not usually diagnosed until age 4, the study presents a remarkable opportunity to intervene before outward symptoms emerge.

IBIS is not the only CAR study looking at how the brain develops and functions in autism. CAR utilizes functional MRI (fMRI) to study brain activity, diffusion tensor imaging (DTI, see image at right) to examine the connections within the brain, and magnetoencephalography (MEG) to understand how fast parts of the brain communicate with each other. Recently, a CAR fMRI study identified a region within the brain that sheds light on why some individuals with autism tend to seek out restrictive interests instead of social activities.



BREAKING DOWN ANXIETY IN AUTISM

John Herrington, PhD loves his job. Make that “jobs” plural. Dr. Herrington is a senior researcher at CAR, with a focus on the co-occurrence of anxiety and ASD. He’s also a practicing clinical psychologist at both the **Anxiety Behaviors Clinic** and the **Department of Child and Adolescent Psychiatry and Behavioral Sciences** at CHOP.

Though dual roles often mean extra hours of work, Dr. Herrington succinctly explains why he’s willing to put in the extra effort: “We need 10 times as many people doing work with kids with autism as we have.” Why anxiety? “More than 40% of children with ASD also have an anxiety disorder. We need to find a way to help them.” Left untreated,

anxiety can lead to poor academic performance, withdrawal, aggression, and even suicide.

Dr. Herrington believes his clinical practice directly informs his research and vice versa. “Research provides me with a broad and deep way of understanding how and why anxiety works. Treating individuals with autism and anxiety allows me to test that understanding every day to make sure the way I think about anxiety really makes sense for any given person.”

Much of Dr. Herrington’s research centers on finding biological indicators of anxiety in children with autism. Through neuroimaging, he’s discovered clues in the brain’s

anatomy that indicate why traditional treatments for anxiety — like cognitive behavioral therapy (CBT) — may be effective for children with ASD and co-occurring anxiety.

Through his clinical practice, however, Dr. Herrington knows that CBT needs to be modified in order to be effective for individuals with ASD. Research conducted by CAR postdoctoral fellow, **Brenna Maddox, PhD**, corroborates Dr. Herrington’s observations. She found that CBT that is modified to treat anxiety in children with ASD led to both reduced anxiety and improved social skills over the long term (one year after the treatment ended).



HEY EXCUSE ME!

Tell your info
Bravo 2

Help the Player respond to the officer's questions. Level: Easy

END

REPEAT OFFICER'S QUESTION

Incomplete response from Player

I NEED MORE INFORMATION

No response from Player

DID YOU HEAR ME?

Player response hard to understand

CAN YOU SAY THAT AGAIN?

Good response

NEXT QUESTION

TRAINING POLICE ISN'T ENOUGH: EMPOWERING INDIVIDUALS WITH AUTISM

Nearly eight percent of children with autism have contact with police officers by the time they graduate high school, and one in five adults with ASD is stopped and questioned by police before age 21. Although many autism advocacy organizations have focused on training law enforcement and other first responders on how to interact with community members with ASD, preventable and traumatic interactions continue to occur.

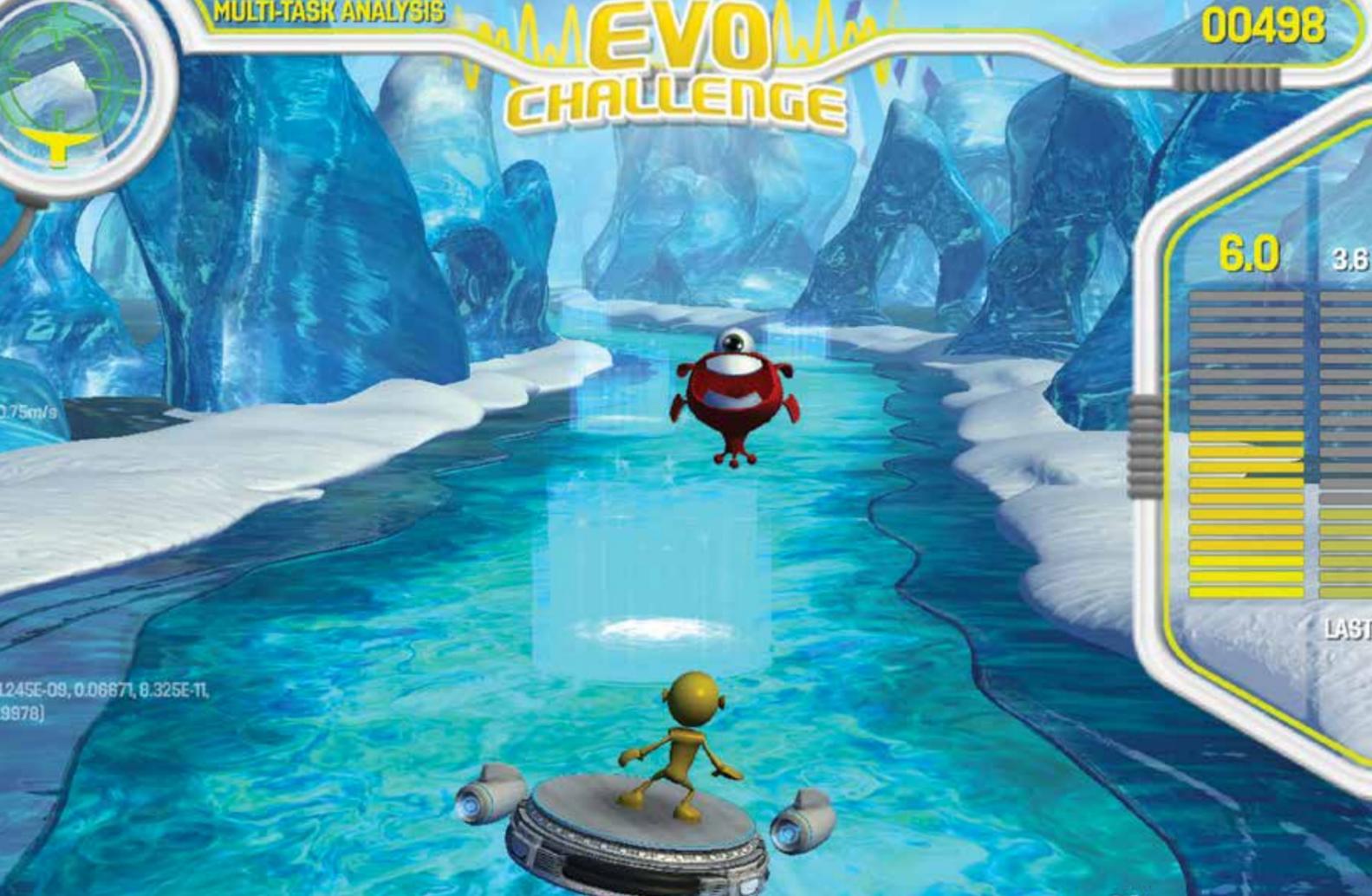
CAR is taking a new approach: educating youth and young adults with autism on how to respond if approached by law enforcement or public safety personnel — using virtual reality (VR).

CAR has partnered with tech-start-up company **Floreo Inc.** and the **Philadelphia Police Department** to test the feasibility of individuals with ASD using VR. Individuals in the VR environment receive live feedback from research staff about police officer expectations and safety concerns. If the technique is proven effective, CAR plans to work with Floreo to expand the options for virtual police interactions and diversify the environments in which they occur.



“Individuals with ASD may be particularly susceptible to poor police interaction outcomes due to difficulty reading social cues,” notes **Julia Parish-Morris, PhD**, a researcher at CAR, who helps supervise the project. “Floreo’s Police Safety Module offers an environment in which users can try out experiences that are hard to stage or replicate in real life. Our hope is if VR can work in this setting, it can also be effective in other scenarios that rely on social communication skill.”





RX: VIDEO GAME 1X/DAILY?

This intervention for kids with autism certainly doesn't feel like therapy. It's a fast-paced video game with 3-D graphics called *Project: EVO*. Designed to improve executive functioning, it requires players to multi-task in order to succeed.

The goal of the game: Drive a hover craft over a winding river while catching the red fish as they jump out of the water. Not the green fish. And certainly not the blue birds. Caution! Avoid running ashore, and steer clear of the icebergs! To succeed in the game, players must improve in their ability to complete a visuo-motor task (navigating the river) and a perceptual

discrimination task (selecting the right color fish) at the same time.

CAR is partnering with *Project: EVO*'s creators, **Akili Interactive Labs**, to test the game as an intervention for children with a dual diagnosis of autism and attention deficit hyperactivity disorder (ADHD). CAR's participation is one step on the road to *Project: EVO* being the first video game with FDA approval for medical use in individuals with autism and co-occurring ADHD. The goal is to obtain FDA approval so that care providers can prescribe the game in the same way they might prescribe a medication for inattention.

Up to 50% of children with ASD and without intellectual disability either meet clinical criteria for ADHD or experience significant symptoms. Frontline medication treatments for ADHD, such as stimulants, have a lower success rate in children with a primary diagnosis of ASD than for children with ADHD alone, and side effects are ten times more likely.

"By playing the game, a player's brain is being trained to ignore distractions and stay focused. Our hope is that these skills will generalize to life outside of the game," explains **Benjamin Yerys, PhD**, Principal Investigator for the study at CAR.

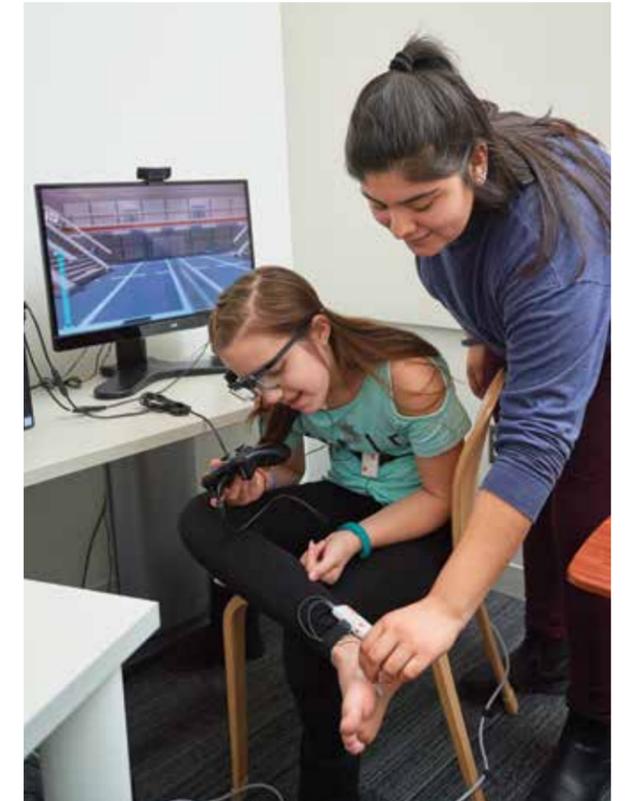
GOOD FOR YOU AND GOOD FUN: BIOSTREAM AND CAR ARE UP FOR THE CHALLENGE

What is it about Angry Birds™ and MarioKart™ that make them so much fun to play? The animations, music, levels, power-ups? If there's a science to creating engaging games that help children on the spectrum improve their social skills, **BioStream Technologies, LLC** and CAR are determined to discover it.

CAR, under the direction of **John Herrington, PhD**, is using its expertise together with BioStream's proprietary research platform to monitor the physiological and behavioral changes in children with autism that occur while they play BioStream's 3D video game. Researchers are looking at changes in heart rate, electrical signals in the brain, facial expressions, eye contact, pupil dilation, and even sweat production. This data will be matched with a player's game behavior to determine which game applications are most engaging and are most likely to drive improvement in social skills.

Why such scientific rigor to design a video game? "We're focused on leveraging next generation technology together with a science-based approach to developing engaging games that are shown to be clinically effective," states **Michael Farber**, BioStream's CEO.

CAR and BioStream are working closely to determine the most rewarding game design with the highest likelihood to improve eye contact and emotional recognition in children with ASD. BioStream will then refine the game for use in a clinical trial conducted by CAR.



"USING TECHNOLOGICAL ADVANCES IN GAMING FOR RESEARCH NOT ONLY GIVES SCIENTISTS NEW WAYS TO TEST INTERVENTIONS AND COLLECT DETAILED DATA OVER TIME, BUT IT HAS THE POTENTIAL TO PROVIDE EFFECTIVE, AFFORDABLE TREATMENTS TO CHILDREN NO MATTER WHERE THEY LIVE."

ROBERT SCHULTZ, PHD, CAR'S DIRECTOR

10 YEARS OF BREAKTHROUGHS



2008

CHOP founds the Center for Autism Research under Director Dr. Robert Schultz.



2008

Under the direction of Dr. Nathan Blum, CHOP adds an autism track to its Leadership Education in Neurodevelopmental and Related Disabilities (LEND) fellowship program.



2009

TIME magazine names discovery of autism gene variants by Dr. Hakon Hakonarson a Top 10 Medical Breakthrough of the Year.



2009

Through ASERT (Autism Services, Education, Resources & Training), CAR partners with Philadelphia organizations to improve quality of care and life for people with ASD in PA.



2009

CAR unveils art gallery featuring artists on the autism spectrum. The original gallery now hangs at Lincoln Financial Field, with copies hanging at CAR.



2010

CHOP and the Philadelphia Eagles partner for 1st annual Huddle Up for Autism fundraiser benefiting autism research and care.



2010

Using MEG, Dr. Tim Roberts discovers that children with ASD process sounds a fraction of a second slower than typically developing peers, leading to cascading delays.



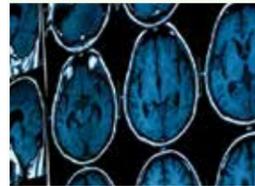
2010

Dr. Robert Schultz and team are first to show that videogames can treat facial recognition deficits in autism.



2011

Drs. Susan E. Levy and Jennifer Pinto-Martin find link between low birth weight and autism, reporting premature infants are 5 times more likely to have autism.



2011

Infant Brain Imaging Study finds that brains of infants who go on to develop ASD follow different developmental trajectory from 6 months of age, affecting brain connections later in life.



2011

CHOP joins Autism Treatment Network (ATN), 12 centers that provide comprehensive care for children with ASD and conduct research to improve healthcare outcomes.



2012

CAR proposes Social Motivation Theory of Autism, which hypothesizes that altered reward pathways in the brain contribute to less motivation for social experiences and uses fMRI to prove that the brain's reward circuitry is compromised in ASD.



2012

CHOP creates Autism Integrated Care program, a coalition of departments caring for autism patients within CHOP. Autism Family Partners provides advice and consultation.



2013

Dr. Robert Schultz and colleagues evaluate compensatory brain networks, language, and general characteristics of children with "optimal outcome."



2014

CAR launches CAR Autism Roadmap™, a comprehensive website to help families and professionals obtain customized, accurate, and up-to-date information and resources.



2014

Dr. David Mandell publishes paper on economic effect of ASD, finding lifetime costs of ASD may reach \$2.4M per individual.



2015

CAR establishes the Technology and Innovation Lab, which focuses on developing new technologies to revolutionize autism diagnosis and treatment.



2016

Dr. Susan E. Levy publishes first-of-its-kind paper on shared decision making between pediatricians and patient families, leading to greater family participation in care decisions.



2016

Dr. David Mandell studies effects of state insurance mandates on spending for ASD, finding mandates are effective in broadening access to autism diagnosis and treatment.

2016

CAR researchers discover that multiple hits to mGluR gene network significantly increase risk for ASD.



2016

Dr. John Herrington finds amygdala has dual role in social deficits and anxiety.



2017

IBIS team finds potential brain biomarker that could help to identify children with ASD in infancy and predict severity.



2017

CHOP creates biorepository for genetic, clinical, and research data.



2017

CAR's Technology and Innovation Lab develops tool to diagnose autism based on 3-minute video of social conversation.



2017

CAR partners with tech companies to create new video games to improve attention and social interactions.



2018

CAR undertakes first-ever longitudinal examination of the effectiveness of universal screening of autism using the M-CHAT.



2018

Dr. Ben Yerys shows that the brain's reward circuitry underlies restrictive interests in autism.



ERIC DREYFUS, *SELF PORTRAIT*, 2009 — Hanging in CAR Art Gallery at Lincoln Financial Field



SUPPORTING PROFESSIONAL SUCCESS AND PERSONAL RELATIONSHIPS

Joe* wasn't exactly an eager participant when he first showed up for a research study designed to help young adults with autism develop professional and personal relationships. His mom had convinced him to go. Having completed high school the previous year, Joe spent his days playing video games in his room. His mom worried about his social isolation. When she heard about the study being run by **Edward (Ted) Brodtkin, MD**, she persuaded Joe to enroll.

In addition to being a CAR-affiliated researcher, Dr. Brodtkin is a psychiatrist and the Director of the **Adult Autism Spectrum Consultation Program at Penn Medicine**. In his experience, reduced motivation to engage with

others, increased social anxiety, difficulties in understanding social cues, and ineffective social skills are all barriers to employment, independence, and overall functioning in adults with ASD. Dr. Brodtkin was determined to design an intervention that would address these concerns. The study in which Joe participated was a pilot study to test the intervention's effectiveness.

Dr. Brodtkin and his team created a program called TUNE-In (Training to Understand and Navigate Emotions and Interactions). The intervention uses personal coaching to enhance motivation and reduce anxiety, and group cognitive-behavioral therapy, supplemented with video modeling, to further teach and practice interpersonal skills. Critical to the intervention is

a third component: group sessions focusing on generalizing these new interpersonal skills through engagement in philanthropic volunteer work.

Preliminary results of the study show significant improvement in participants' measures of social ability and the number of social relationships in day-to-day life. As for Joe, over the course of the study, he became increasingly comfortable and more interested in how working on social functioning could help him pursue some of his own goals, including feeling capable enough socially to go to a gaming meeting.

**Joe is a fictional composite of several participants from the study.*

“IT WAS WONDERFUL TO BE ASKED THE THINGS THAT ARE EXACTLY MY IMMEDIATE SOCIAL STRUGGLES, VALIDATING MY FEELINGS AND PUTTING INTO WORDS THE FLOATING ANXIETY OF BEING AN OLDER SOCIALLY ISOLATED ASPIE... IT MADE ME FEEL NOT-CRAZY. I APPRECIATE IT.”

ADULT PARTICIPANT IN THE QUALITY OF LIFE STUDY



FINDING A WAY TO MEASURE WHAT MATTERS

There’s a motto in business: “what gets measured gets done.” CAR’s Clinical Training Director, **Judith Miller, PhD**, hopes that adage doesn’t apply to autism — at least not yet.

Currently, there is no tool to measure quality of life outcomes for individuals with ASD. Given that quality of life is a main goal of many interventions and services, that’s a problem. “Without an accurate measure of quality of life in autism, clinicians are at a disadvantage when it comes to determining client needs, reviewing progress, setting priorities, and evaluating service appropriateness and effectiveness,” says Dr. Miller.

There are other quality of life measures available, but none are specific to autism. Because quality of life is a multidimensional and highly individualized concept, it is important to develop a measure that is sensitive to the unique circumstances of life with autism, including personal factors like the individual’s interests and abilities, and environmental factors, like the resources that are available when help is needed.

Led by Dr. Miller and postdoctoral fellow **Laura Graham Holmes, PhD**, the CAR team is field testing quality of life items related to companionship, emotional support, resources, satisfaction with social roles and activities, and sexual function and satisfaction. The team is surveying 600 individuals with autism from age 5–65 and their parents (as appropriate). Participants also have the chance to recommend additional subject areas so that the researchers can work on supplemental items to be added to an ASD-specific quality of life measurement tool.

OBESITY IS A WEIGHTY ISSUE FOR INDIVIDUALS WITH ASD

Children, adolescents, and young adults with autism are up to two times more likely to be overweight and up to five times more likely to be obese than typical peers. “Those are alarming statistics,” says **Susan E. Levy, MD, MPH**, CAR’s Medical Director.

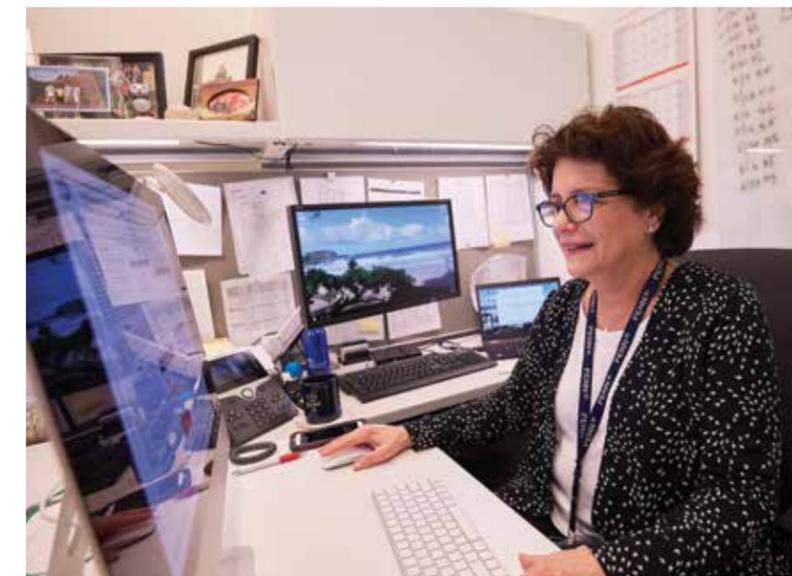
Before joining CAR, Dr. Levy founded the Regional Autism Center (RAC) at CHOP (now the **Autism Integrated Care Program**) in 1999. At the time, RAC was one of the country’s few specialty centers caring for children with ASD.

Dr. Levy says that over the course of her career, doctors have become increasingly concerned about obesity in individuals with ASD. “We need research to fully understand the scope of the problem of obesity in individuals with autism, what role physical activity and food selectivity may play in obesity, and what interventions may be used to reduce the risk of abnormal weight gain and improve overall well-being.”

Emily Kuschner, PhD, a CAR researcher and clinical psychologist, has developed a program called Building Up Food Flexibility and Exposure Treatment (BUFFET), which helps children with autism learn to expand their palate through cognitive behavioral skills

and exposure therapy. She and Dr. Levy are partnering with colleagues at the **University of Pennsylvania** to develop a smartphone app to help children with autism cope with food selectivity and expand the variety in their diets.

CAR researcher **Joseph McCleery, PhD** is also developing an app. Designed for older children and adults with autism, the app sends automated activity reminders, interactive prompts for realistic daily goal setting, automated activity progress reports, and positive feedback. Prior studies have shown that physical activity improves short-term cognitive performance, reduces stress and anxiety, and has positive short- and long-term effects on mood.





MAKING THE MOST OF SCHOOL-BASED INTERVENTIONS

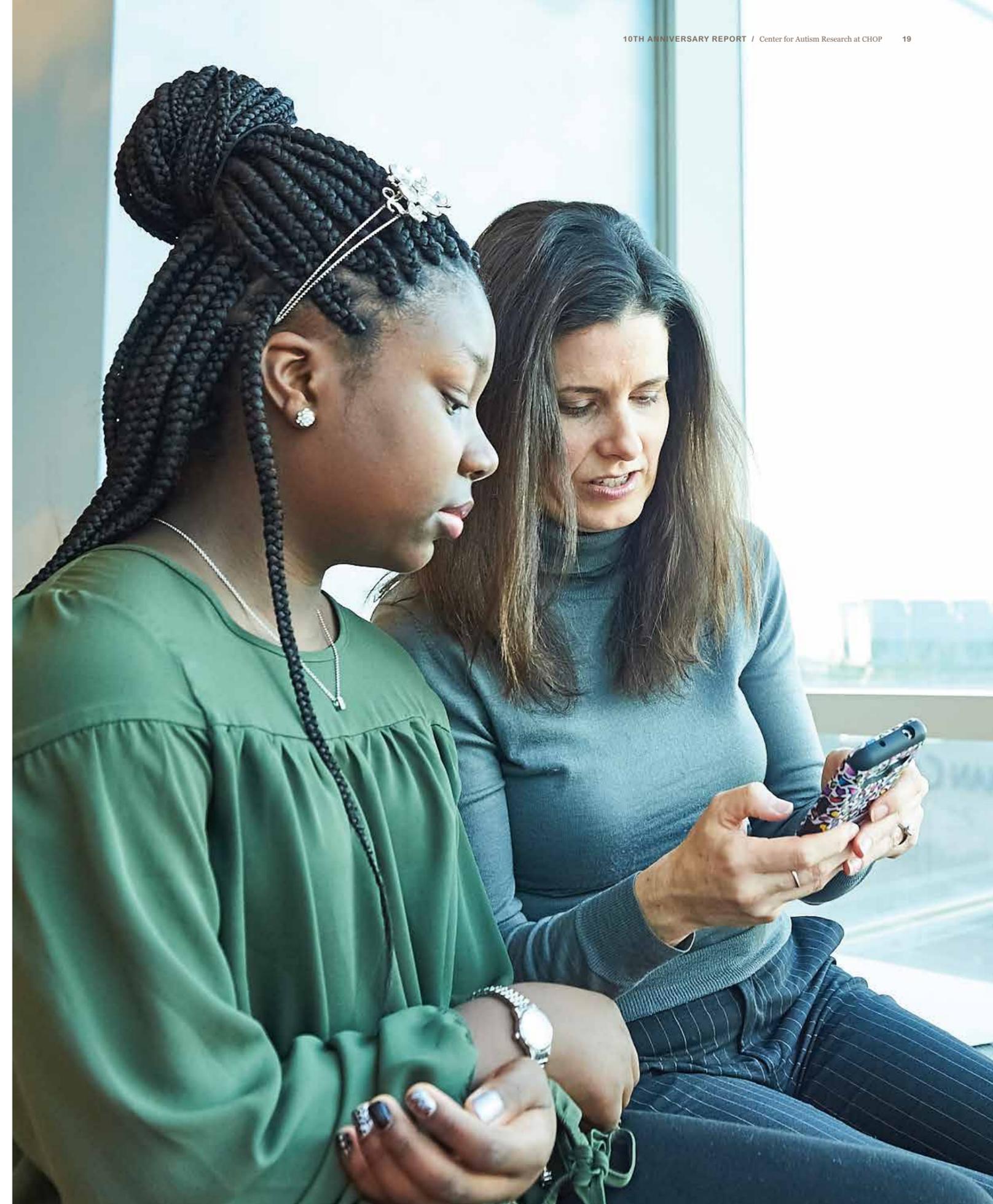
Most children with autism receive the majority of their care in school. That presents a wonderful opportunity, according to CAR's Associate Director, **David Mandell, ScD of Penn Psychiatry**, who is helping to ensure that schools make informed choices when deciding which interventions to implement in the classroom.

Dr. Mandell is not new to this work. In 2008, he initiated his first randomized control trial to help the **School District of Philadelphia** test an intervention program for its youngest students. Although the study ended several years ago, Dr. Mandell and his team continue to train teachers and aides in the District today.

Dr. Mandell is now in the District evaluating the use of a computer-assisted intervention for autism called TeachTown®. TeachTown® blends computer-delivered and teacher-led ABA instruction to teach academic, social, and emotional skills. The computerized instruction component adapts to a student's progress and includes embedded games and animation as reinforcers.

Dr. Mandell will study whether the program is effective in teaching kids skills, but he's most interested in how the use of the computerized intervention affects teachers' use of other evidence-based practices: "While computer-assisted interventions may increase instructional time for students with autism, they may also have unintended consequences, such as reducing how much interaction students have directly with their teachers."

Dr. Mandell's team is also conducting research in Philadelphia preschools to analyze the type and quality of intervention being delivered in inclusive versus non-inclusive settings. His goal is to parse out which settings are best for which children. According to Dr. Mandell, "by comparing outcomes of different early intervention practices and investigating intervention-child fit in community-based settings, we hope to make complex early intervention placement decisions easier for both parents and providers."





TELEHEALTH FOR AUTISM: LEVERAGING TECHNOLOGY TO DIAGNOSE AND TREAT ASD

Amanda Bennett, MD has been a developmental and behavioral pediatrician at CHOP since 2008. She estimates she has treated almost 1,500 patients with autism over the course of her career. Each patient she treats helps inform her care for others. “It’s taken years of watching patients grow up and gain new skills to be able to provide the necessary anticipatory guidance that most families are seeking,” she explains.

Dr. Bennett’s patients benefit from her years of experience, but not every doctor will encounter as many patients with autism as she has. Telehealth is a way to help bridge that gap.

Dr. Bennett recently completed a study, in collaboration with the **Autism Treatment Network/Autism Speaks®**, using an innovative telehealth-based platform that connects local primary care providers (PCPs) with specialists like her. The Autism ECHO

study — Extension for Community Healthcare Outcomes — matched a team of five autism specialists (Dr. Bennett, accompanied by a psychologist, family navigator, dietician, and a parent) with 15 PCPs from underserved communities. For six months, the group met twice a month for 2-hour virtual clinics.

Findings show that the participating PCPs significantly improved their abilities to screen for and to manage autism. This is critical because with the increased prevalence of ASD, diagnostic and treatment demands far exceed the capacity of specialty centers, like CHOP’s **Division of Developmental and Behavioral Pediatrics**, where Dr. Bennett works. The ECHO Autism project is now being expanded to include more PCPs throughout the tristate region, with an innovative ECHO extension focused on transition to adulthood for training pediatric and adult care specialists about the needs of patients with autism.



FRANKLY, THE NEED IS CLEAR: IMPROVING DIAGNOSIS AND SCREENING FOR AUTISM

Early diagnosis and early intervention lead to better long-term outcomes for individuals with ASD. However, children often wait months or even over a year to receive a diagnostic evaluation from an ASD specialist. With increased rates of autism being reported over the last few years, there is an urgent need for more providers — including non-ASD specialists — who are able to confirm a diagnosis of autism, particularly for children whose clinical presentation is fairly clear (or “frank”).

Judith Miller, PhD, CAR’s Clinical Training Director, in conjunction with the **Division of Developmental and Behavioral Pediatrics** and primary care providers (PCPs) at CHOP, recently began a project to design clinical tools to assist non-specialists in making an ASD diagnosis. The team worked closely with stakeholders, including PCPs, parents, and Early Intervention agencies, to learn their needs and constraints.

The new tool will be used to make a diagnosis of autism in children whose presentation is very clear, or to provide an informed referral when the presentation is not as evident. The team is also developing a clinical decision tree for PCPs and scripts for providing families basic information about next steps after a diagnosis. The overall goal is to reduce wait times and facilitate a quicker pathway to intervention.

Separately, Dr. Miller is developing a smartphone app to assist parents in recognizing one of the red-flags for autism: a child’s failure to respond to his or her name, and **Whitney Guthrie, PhD**, a postdoctoral fellow at CAR, is researching ways to improve upon current autism screening practices. 25,000 autism screenings took place at CHOP in 2017 across 31 primary care practices, providing Dr. Guthrie with an incredibly vast dataset to evaluate whether the screener being used adequately identifies children with ASD without wrongly flagging others. Her results show that current screening methods have a lot of room for improvement, a gap which CAR is trying to fill using technology-based measurements of toddler behavior and language.

IMPROVING CARE FOR ADULTS

CAR recently partnered with two community mental health centers in Philadelphia to improve treatment for adults with autism and co-occurring psychiatric disorders. After evaluating a subset of patients in the centers, CAR found that 8% of the patients have autism. Two-thirds had not been identified previously. CAR also found individuals who had an incorrect diagnosis of autism.

As part of the study, CAR trained providers at both locations to recognize features of autism and to adapt their support services to work effectively for adults with ASD. CAR is also helping the clinicians to provide a modified cognitive behavioral therapy (CBT) treatment for adults with autism.



THE FUTURE OF AUTISM RESEARCH AND CLINICAL CARE: THE AUTISM LEARNING HEALTH SYSTEM

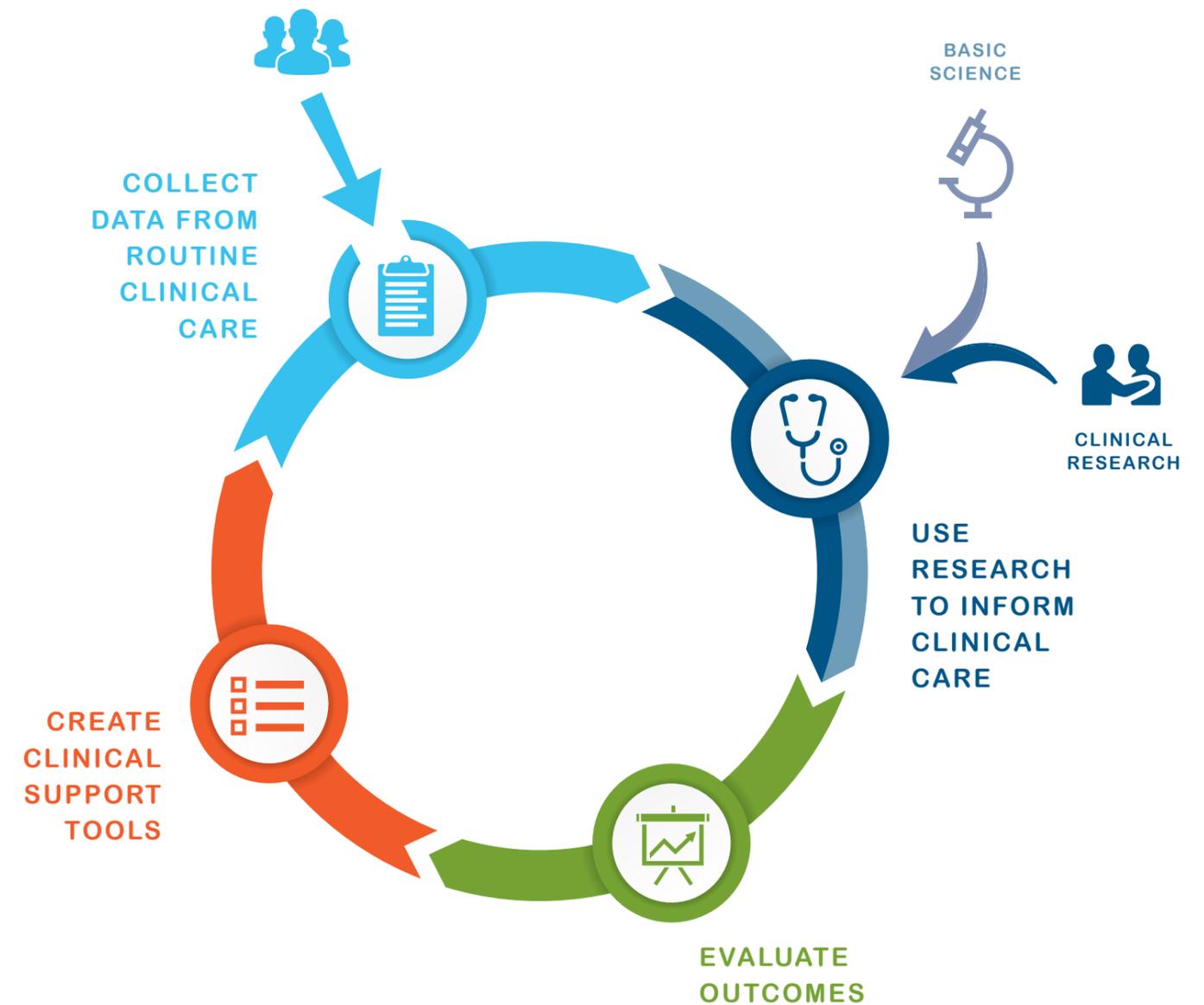
Imagine a clinician being able to compare an individual patient’s features to an enormous reference set in order to learn what kinds of testing procedures should be ordered and what kind of treatment options are likely to succeed. The goal is simple: to deliver the right treatment to the right person at the right time.

With over 20,000 office visits, CHOP cares for more than 10,000 individuals with ASD annually. Particularly with CAR’s new technology (see page 4), each visit, and each patient, provides an opportunity to grow this reference

set by gathering important pieces of quantitative data about health and development, behavioral progress, treatment methods, co-occurring conditions, sleep, diet, mood, and more.

With generous support from the **Eagles Charitable Foundation**, CAR has begun to build this vision into a reality. The **Autism Learning Health System (LHS)** is being developed in collaboration with multiple clinical departments at CHOP and will drive the process of discovery as a natural outgrowth of clinical care.

Analyzing CHOP’s wealth of clinical data from a heterogeneous patient population, researchers will be able to uncover overarching patterns in ASD characteristics, treatments, and outcomes. As CHOP’s LHS matures, it will link with healthcare systems across the country to share data and develop more accurate clinical support tools. This will open the door for doctors across the nation to give each patient a personalized, evidence-based care plan that can be measured and tailored at each visit.



A LEARNING HEALTH SYSTEM CREATES A CONTINUOUS LOOP BETWEEN CLINICAL CARE AND RESEARCH THAT PROVIDES ONGOING DISCOVERY AND INNOVATION TO ENSURE THE HIGHEST QUALITY HEALTHCARE ACROSS THE LIFESPAN.

**ADVANCING
THE
MISSION**

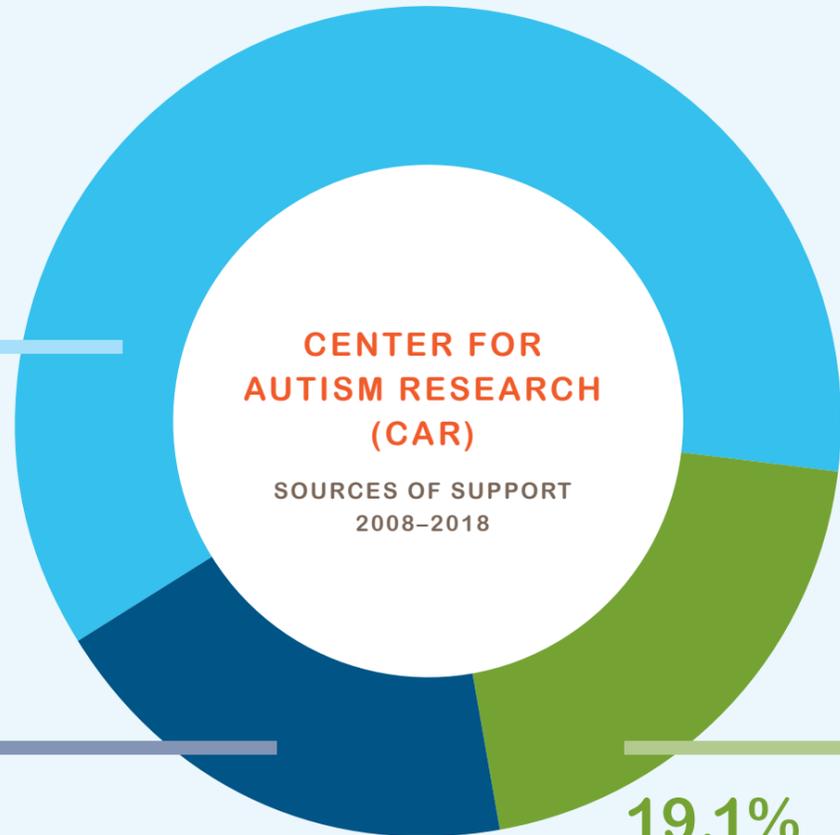
60.8%
RESEARCH GRANTS
AND CONTRACTS*

20.1%
PHILANTHROPY

Philanthropy supports a diverse set of activities:

- Establishment of the Technology and Innovation Lab
- Genetic specimen collection and creation of a new biorepository
- Foundational support for the Autism Learning Health System
- Training of primary care clinicians to diagnose and treat ASD
- Creation of online phenotyping questionnaires, facilitating renewal of \$6.5M NIH grant
- Pilot research on anxiety and autism, facilitating \$2M industry grant
- Pilot funds for junior investigators to launch independent research
- CAR Autism Roadmap™
- *Next Steps* workshops and *Distinguished Lecture Series*
- Subsidized support for dozens of funded research studies

* includes federal, private foundation, industry, state, and university-based grants



19.1%
CHILDREN'S
HOSPITAL OF
PHILADELPHIA

**MANY THANKS
TO CAR'S
GENEROUS
FAMILIES AND
SUPPORTERS
WHO HELP
ADVANCE THE
MISSION EVERY
DAY!**

**CAR'S
NEW
HOME**

CAR moved into its new home in the Roberts Center for Pediatric Research in Spring 2017. Set alongside the Schuylkill River, the glass building affords families and staff incredible views of South Philadelphia. An open floor plan on the 5th floor encourages collaborative work, while the 4th floor's Family Research Center provides private assessment rooms, multiple waiting areas, specialized dry lab spaces (including a markerless motion capture lab, electrophysiology lab, and mock MRI), and work stations for family use.



