

Autism now affects 1 in 68 children and 1 in 42 boys • Autism is one of the fastest-growing developmental disorders in the U.S. • Boys are nearly five times more likely than girls to have autism • One-third of young adults with autism are disconnected from work and continued education after high school

DREXEL UNIVERSITY / **A.J. DREXEL AUTISM INSTITUTE ANNUAL REPORT 2016**



MESSAGE FROM DREXEL'S PRESIDENT



Drexel University is proud and fortunate to have the A.J. Drexel Autism Institute on its campus.

The institute was founded in 2012 and in just a few years has distinguished itself as one of the leading centers for autism research in the country. The institute has built on our Dornsife School of Public Health's tradition of autism public health science — it is one of only a handful of university-based research groups to have earned the National Institutes of Health's Autism Center of Excellence Award. Over time, I believe the A.J. Drexel Autism Institute will help to shape policy surrounding autism.

This is especially good news for the estimated 5 million adults in the country who are living with autism and the 1 in 68 newborns who have this disorder. That includes my nephew Jack, a teenage boy who is on the spectrum.

The A.J. Drexel Autism Institute is unique in that its main objective is to discover and implement approaches to prevent the morbidity and disability associated with autism. At the same time, the institute's focus on population-based strategies is designed to bring more effective treatments and approaches to enable people with autism to lead healthier and more fulfilling lives.

To be sure, these are lofty goals, but the institute is off to a great start, thanks to the world-renowned team of investigators who have come from across the country to do this important work.

The team is led by Director Dr. Craig Newschaffer, a professor in the Department of Epidemiology and Biostatistics at Drexel's Dornsife School of Public Health; Dr. Diana Robins,

program area leader of the Early Detection and Intervention Research Program, and associate professor of Psychology in the College of Arts & Sciences, and Community Health & Prevention in the Dornsife School of Public Health; and Dr. Paul Shattuck, program area leader of the Life Course Outcomes Research Program and an associate professor in Health Management and Policy in the Dornsife School of Public Health. All of the researchers have distinguished themselves through their path-breaking work that is designed to better understand, diagnose and treat those on the autism spectrum.

But don't just take my word for it. As you read through this report you will see the research team has already attracted national attention and millions in funding. After receiving initial support from Drexel and a generous gift from the Charles and Barbara Close Foundation to launch the institute, our researchers have also received a number of prestigious grants, including more than \$3 million from the National Institutes of Health and an anonymous gift of \$3.6 million from a generous benefactor. The institute also has an additional \$2.8 million in pledged support. Four publications authored or co-authored by institute researchers were included in the top 20 most influential advances in autism research in 2015.

The institute is a jewel here at Drexel. This report details some of the exciting initiatives taking place there. I believe this is just the beginning of the many life-altering advancements to come from the institute.

Sincerely,

John A. Fry

A.J. DREXEL AUTISM INSTITUTE AUTISM RESEARCH FOR SOCIAL CHANGE

DREXEL UNIVERSITY
A.J. Drexel
Autism Institute
Administrative Reception



The A.J. Drexel Autism Institute launched as a free-standing, university-level research institute in July 2012, thanks to the support of President John A. Fry and a generous gift from the Charles and Barbara Close Foundation.

The A.J. Drexel Autism Institute is the first in the country focused on applying public health science to the societal challenges posed by autism spectrum disorder (ASD), a serious set of neurodevelopmental disabilities that fundamentally alter individuals' abilities to interact and communicate. The institute's focus is a major shift from most other research centers built around the pursuit of a cure. While biomedical breakthroughs are always welcome, the institute's mission is to discover, develop, promote and disseminate population-level and community-based approaches that will prevent autism-associated morbidity and disability and improve the quality of life for individuals of all ages on the spectrum.

In a short span, the institute has quickly recruited a leading team of investigators, established staffing and infrastructure, and has implemented an accelerated program of community engagement. Equally impressive, its innovative approach to autism research has attracted more than \$5 million in philanthropic support in its first four years.

In addition to the program area leaders highlighted in this first edition of the annual report, the A.J. Drexel Autism Institute has a core of dedicated junior faculty members and senior staff who have taken the lead on exciting projects of their own which will comprise the core of forthcoming reports.

Our researchers work in three research program areas:

MODIFIABLE AUTISM RISK FACTORS EARLY DETECTION AND INTERVENTION LIFE COURSE OUTCOMES

Together, these teams are already leading the way in bringing large-scale, population-focused strategies to the autism research landscape in pursuit of the following:

- **DISCOVERING PREVENTABLE CAUSES OF AUTISM SPECTRUM DISORDER.**
- **REDUCING THE AVERAGE AGE OF ASD DIAGNOSIS.**
- **OPTIMIZING THE ORGANIZATION OF ASD-RELATED SERVICES RECEIVED BY FAMILIES.**
- **BUILDING EVIDENCE ON THE EFFICACY OF CURRENT AND PROPOSED INTERVENTIONS.**
- **EDUCATING COMMUNITIES ABOUT EFFECTIVE INTERVENTIONS, ESPECIALLY AMONG THE UNDERSERVED.**
- **LEARNING HOW ADOLESCENTS AND YOUNG ADULTS WITH AUTISM CAN LEAD MAXIMALLY INDEPENDENT AND FULFILLING LIVES.**
- **SHARING SCIENTIFICALLY ACCURATE INFORMATION ABOUT AUTISM WHILE RESPECTING COMMUNITY PERSPECTIVES.**
- **SHAPING PUBLIC POLICY AT ALL LEVELS TO HELP IMPROVE THE LIVES OF THOSE AFFECTED.**

To help meet our mission, these programs collaborate with two other groups:

CLINICAL CORE – a team of licensed psychologists and behavior analysts with the expertise to conduct psycho-social, behavioral and neuropsychological assessments.

OUTREACH CORE – the institute's main connector to individuals with autism spectrum disorders, their families and caregivers, service providers and advocacy groups.

The institute also houses a **POLICY ANALYSIS CENTER** built to support governmental agencies charged with running public service programs assisting those on the spectrum. Examples of initiatives supported by the center include the Pennsylvania Southeast Regional Autism, Services, Education, Resources, and Training (ASERT) Collaborative, a contract with the Commonwealth of Pennsylvania and part of a State Bureau of Autism Services network supporting individuals with autism through expertise in clinical, data and policy projects, and a statewide resource center that connects individuals with autism, their families and professionals to relevant information, events and trainings; and the Philadelphia Autism Project, the first municipal effort of its kind to engage stakeholders across systems and in every corner of the city in specific initiatives that improve the lives of Philadelphians living with autism and their families.

• Autism spectrum disorder (ASD) is a set of neurodevelopmental disabilities

that fundamentally alter individuals' abilities to interact and communicate. •



THE MODIFIABLE AUTISM RISK FACTORS RESEARCH PROGRAM SEEKS TO DISCOVER EXPOSURES OR BEHAVIORS THAT IF REDUCED, ELIMINATED OR CHANGED WOULD LOWER AUTISM SPECTRUM DISORDER DISABILITY, IMPAIRMENT AND MORBIDITY. IT IS HEADED BY A.J. DREXEL AUTISM INSTITUTE DIRECTOR **DR. CRAIG NEWSCHAFER**, A PROFESSOR IN THE DEPARTMENT OF EPIDEMIOLOGY AND BIostatISTICS IN DREXEL'S DORNSIFE SCHOOL OF PUBLIC HEALTH.



SEARCHING FOR PREVENTABLE CAUSES

A.J. Drexel Autism Institute Director Dr. Craig Newschaffer is one of the world's premier autism researchers. He focuses on identifying modifiable risk factors that might lead to the prevention of adverse behavioral effects in certain individuals with autism.

Since 2008, Dr. Newschaffer has been leading the Early Autism Risk Longitudinal Investigation (EARLI), a one-of-a-kind, long-term study of pre-, peri- and neonatal risk factors and risk biomarkers for autism spectrum disorder.

The EARLI study, initially funded as a National Institutes of Health "Center of Excellence" project, is one of the most extensive ongoing epidemiologic studies to understand the complex causes of autism. Dr. Newschaffer's groundbreaking research follows hundreds of mothers who have previously had a child with autism, from the start of a subsequent pregnancy through delivery. He and his team then follow these children through age 3 to assess behaviors indicative of autism and to identify any associated environmental factors.

The ultimate goal of this work is to improve quality of life for the individuals and families affected by autism by understanding contributing causes that could be avoided. Brain changes linked to autism begin during the prenatal period. If, for example, the Modifiable Risk Factors Program discovers that certain environmental pollutants play a part in changing the brains of genetically susceptible individuals in utero, this might support regulatory changes that could alter the lives of future generations.

“The EARLI study is truly groundbreaking

because it is one of the few studies that focuses on the prenatal window. Even though we know that autism is heritable and that genetics are important to the cause of autism, we ultimately can't change our genetics. We can change other factors that work with genetics to contribute to the brain changes behind autism. Since we're studying a population that has a higher baseline genetic risk for autism, it's easier to find these other factors. ■ Five years after we started the EARLI study, we have a cohort of moms and infants in place, as well as a huge, very rich biologic repository of samples. This rare collection is remarkable because there aren't a lot of repositories like it in the world, and it gives us the ability to answer a number of research questions going forward.

-Dr. Craig Newschaffer

The Exposure Science Laboratory examines maternal or neonatal samples to detect developmentally related signals.

200 samples

come through this lab on a weekly basis and approximately 20,000 tests have been completed since its inception in 2014.

PROJECTS

Major projects using samples from EARLI and other autism studies are currently underway at the institute's state-of-the-art Exposure Science Laboratory. The lab conducts research to pinpoint naturally occurring or external chemicals inside the body that are contributing to autism spectrum disorder. The laboratory works with investigators within the Modifiable Autism Risk Factors program, pursues its own studies and collaborates with other investigators.

Lab researchers are currently looking for evidence of autism risk factors by studying samples — blood, urine and newborn meconium — collected from mothers and their children.

Future projects will use cord blood to look for thousands of environmental exposures that may be associated with autism spectrum disorder and will examine placental tissue to quantify chemical modifications of the genes in pregnancies at risk for an autism disorder.

OUTREACH

Each year, the A.J. Drexel Autism Institute hosts a signature event called the Autism & Public Health Lecture. The lecture series brings top researchers to Philadelphia to discuss the latest public health research on autism. For example, Dr. Heather Volk from Johns Hopkins University School of Public Health was a guest speaker on air pollution and autism. Lectures are open to the community and offer researchers the opportunity to engage with a general audience on the implications of their research.



THE EARLY DETECTION AND INTERVENTION RESEARCH PROGRAM AIMS TO BETTER LINK EARLY DETECTION WITH EARLY INTERVENTION RESEARCH. RESEARCH PROGRAM AREA LEADER AND ASSOCIATE PROFESSOR OF PSYCHOLOGY IN THE COLLEGE OF ARTS & SCIENCES, AND COMMUNITY HEALTH & PREVENTION IN THE DORNSIFE SCHOOL OF PUBLIC HEALTH DR. DIANA ROBINS, ALONG WITH FELLOW RESEARCHERS, EVALUATES METHODS OF DISSEMINATING SCREENING, DIAGNOSIS AND TREATMENT TO CHILDREN IN THE COMMUNITY AND WAYS TO ADAPT EXISTING INTERVENTIONS TO THE NEEDS OF UNDERSERVED CHILDREN AND FAMILIES.



RACING TO PROVIDE EARLY INTERVENTION

“As a scientist, I have seen a lot of folks who focus on basic research,

where the acquisition of knowledge is itself the end. For me, it's always been a bigger picture of what to do with this knowledge to make the world a better place. When we see families struggling to find services, or struggling to get answers about their child, and what we know in the lab doesn't translate, I feel like we haven't done our job yet. You want science to have real impact. ■ One of the gaps in the field is taking kids detected through screening and getting them right into treatment studies to show that there's a connection. That package is what will really shift the standard that's out there in the world.”

-Dr. Diana Robins

Much of Dr. Diana Robins' work centers on refining a widely used screening tool for autism spectrum disorders she developed called the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F). The M-CHAT-R/F tool can alert caregivers that a child may be displaying early signs of autism spectrum behavior.

It is known that children with autism spectrum disorders who receive earlier diagnosis and intervention have better outcomes. However, fewer than

20 percent of the nation's pediatricians are following all of the early detection recommendations, which call for ongoing surveillance, broad screening at three ages, and ASD screening at 18 and 24 months. This creates a challenge for identifying children on the spectrum earlier so that they can take advantage of treatments while they're young enough to benefit the most.

Dr. Robins seeks to expand research on early detection to other community settings such as community health

centers and preschools as well as to find ways to deliver interventions more quickly and efficiently to families after autism has been diagnosed. She is partnering locally, nationally and internationally with other universities to assess the complex screening and early detection needs of a range of communities.

The goal of her research program is to link early screening to early diagnosis, which will lead to earlier and more effective interventions.

PROJECTS

The Early Detection Project, funded by the Eunice Kennedy Shriver National Institute for Child Health and Human Development, is one example of how the Early Detection and Intervention team is searching for early signs of autism. The team works with the Clinical Core to study patient evaluations and provide parents and those with autism earlier diagnoses and tools to better manage the complex issues that come with an autism diagnosis.



OUTREACH

Community relationships are crucial to informing research projects at each step of the process, from submitting grants to recruiting participants. This is especially true when it comes to early detection. The Early Detection and Intervention team relies on Outreach Core members who build meaningful relationships and partnerships with community members on behalf of the institute.





THE LIFE COURSE OUTCOMES RESEARCH PROGRAM SEEKS TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE ON THE AUTISM SPECTRUM AND THEIR FAMILIES BY INFORMING AND ASSESSING PROGRAMS, POLICIES AND SUPPORT SYSTEMS. THE PROGRAM IS COMMITTED NOT ONLY TO PUBLISHING ITS FINDINGS IN SCIENTIFIC JOURNALS BUT ALSO TO MAKING ITS FINDINGS ACCESSIBLE IN DIGESTIBLE AND JARGON-FREE FORMATS (LIKE WEBSITES, BLOGS, SOCIAL MEDIA POSTS, AND FACT SHEETS). THE RESEARCH PROGRAM AREA IS LED BY DR. PAUL SHATTUCK, AN ASSOCIATE PROFESSOR IN HEALTH MANAGEMENT AND POLICY IN THE DORNSIFE SCHOOL OF PUBLIC HEALTH WHO IS AN ACKNOWLEDGED LEADER IN THE FIELD.



DRIVEN TO IMPROVE ADULT LIVES

“The national statistics we produce about things

Dr. Paul Shattuck’s research seeks to understand the service needs of adults with autism, and the range of health and social outcomes they typically experience. His work explores indicators related to employment, education, services and social

participation — going far beyond theory to find practical applications. This work covers largely uncharted waters in autism research.

The “life course” approach looks at the roles an individual assumes and the services systems an individual interacts

with over their entire life span. The experiences of receiving a diagnosis, accessing needed services, transitioning into adulthood, finding employment, continuing education and participating in the community are all vital stepping stones on the path to a high-quality life.

like employment, health and educational outcomes shape our understanding of where we need to improve efforts to help people on the autism spectrum. We build the gauges to see if the billions spent on research and services are moving the needle on these outcomes. ■ Our work is routinely used by members of Congress, business leaders, advocacy organizations, families, schools and state agency directors to know where problem-solving efforts need to be directed. Our statistics and indicators reveal the scope and magnitude of problems facing people on the autism spectrum and whether we are making progress toward improving outcomes as a nation. Community- and population-level statistics are an essential counterbalance to research that develops interventions. ■ It’s not enough to know whether a technique creates an effect in a tightly controlled setting. We also need to know if things are getting better or worse for the entire population.”

-Dr. Paul Shattuck

PROJECTS

The Life Course Outcomes team oversees Project SEARCH, a one-year high school transition program for students with autism and intellectual disabilities. Students in the program supplement their classroom studies with a series of three, 12-week internships at Drexel University. During their internships, they acquire marketable skills while receiving support from job coaches, a site mentor and a job developer — with the ultimate goal of obtaining employment once the program ends.

Members of the Clinical Core assist by designing performance-based activities and assessments of both the participants and the working environment so that Project SEARCH interns are successful on the job. Life Course Outcomes researchers are looking to understand and document the “active ingredients” that determine whether Project SEARCH is successful.



OUTREACH

The A.J. Drexel Autism Institute does more than research. It also works with those with autism and their families to give them the tools needed in daily life. One way the institute has done this is by using comedy to open up discussions about autism disorders.



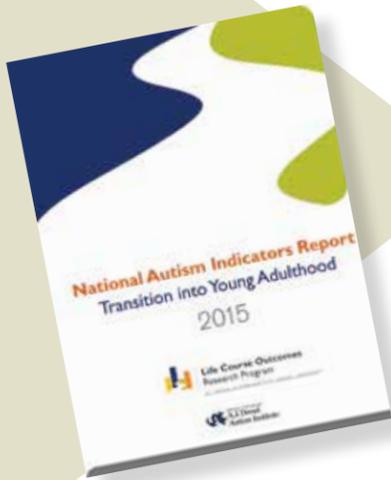
In 2015, members of the institute’s Outreach Core hosted Asperger’s Are Us, a comedy troupe comprised of young adults on the autism spectrum. After the performance, the troupe candidly discussed their experiences of growing up on the spectrum and how it affects their daily life — giving audience members a window into life with autism.

NATIONAL AUTISM INDICATORS REPORT

Little data has been collected and analyzed to date to inform public policies related to adults on the spectrum. The Life Course Outcomes team intends to change that.

The team produces a “National Autism Indicators Report” series that examines large national datasets to develop baseline indicators on topics such as transitioning to adulthood and vocational rehabilitation. In 2015, the federal Interagency Autism Coordinating Committee named the team’s report one of the year’s most influential advances in autism research, out of a field of roughly 4,200 autism research publications. The 2016 report focused on Vocational Rehabilitation, a system designed to provide support to states for implementation of services to assist people with disabilities to prepare for, find and keep employment.

Building on the success of the series, Dr. Shattuck and his team are working to create a National Autism Data Center to serve as a one-of-a-kind “census bureau” of autism statistics. The National Autism Data Center will analyze information from around the country to produce meaningful statistics that policymakers can use to advocate for effective programs and services for individuals on the autism spectrum.



In 2015, the federal Interagency Autism Coordinating Committee named the team’s report one of the year’s most influential advances in autism research, out of a field of roughly 4,200 autism research publications.

An analysis of life outcomes for post-high school adults with ASD

 Education	<p>Attended any postsecondary education</p> <p>36%</p> <p>Ever attended 2- or 4-year college, or vocational/technical school</p>	<p>Attended any college</p> <p>30%</p> <p>Ever attended 2- or 4-year college</p>
 Employment	<p>Had a job for pay</p> <p>58%</p> <p>Ever had a job for pay outside of the home</p>	<p>Had a job soon after high school</p> <p>32%</p> <p>Ever had a job for pay outside of the home within the first two years after leaving high school</p>
 Living Arrangements	<p>Lived independently</p> <p>19%</p> <p>Ever lived away from parents without supervision</p>	<p>Lived apart from parents</p> <p>31%</p> <p>Ever lived away from parents with or without supervision</p>
 Social & Community Participation	<p>Any socialization</p> <p>76%</p> <p>Ever (in the past year) saw friends, called friends, or was invited to activities</p>	<p>Any community participation</p> <p>68%</p> <p>Ever (in the past year) was involved in volunteer activities, community activities, or took classes or lessons</p>
 Access to Services	<p>Received any services</p> <p>74%</p> <p>Ever received at least one service after high school</p>	<p>Received vocational services</p> <p>37%</p> <p>Ever received any vocational services or job training after high school</p>
 Health and Safety	<p>Co-occurring conditions</p> <p>60%</p> <p>of adolescents had two or more additional health or mental health conditions.</p>	<p>Bullying victimization</p> <p>47%</p> <p>of youth were victims of bullying during high school.</p>

THE WORLD TAKING NOTICE



A.J. DREXEL AUTISM INSTITUTE IN MAJOR NEWS MEDIA

Journal of Autism and Developmental Disorders

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

The Economist

JAMA
Journal of the American Medical Association

npr



Journal of Autism and Developmental Disorders

Dr. Diana Robins first authored, with several other autism institute co-authors “Universal Autism Screening for Toddlers: Recommendations at Odds” in the *Journal of Autism and Developmental Disorders* to refute the United States Preventive Services Task Force’s claim that there is insufficient evidence to recommend or discourage early screening for autism in all children.

Autism Speaks

Dr. Craig Newschaffer’s 2015 article showing that MMR vaccine did not increase autism risk in younger siblings of children with autism was listed as No. 3 on Autism Speaks’ list of Top 10 research stories of 2015.

The Economist

An article in *The Economist* examined why children in the developed world are far more likely to be diagnosed with autism than in the past, using data presented by the A.J. Drexel Autism Institute.

Journal of the American Medical Association

An article further dispelling the link between autism and vaccines by Dr. Craig Newschaffer in the *Journal of the American Medical Association (JAMA)* in 2015 is the No. 34-ranked paper of all time in terms of online attention out of more than 5 million papers tracked, and is the third most-popular paper published by *JAMA* ever.

Pediatrics

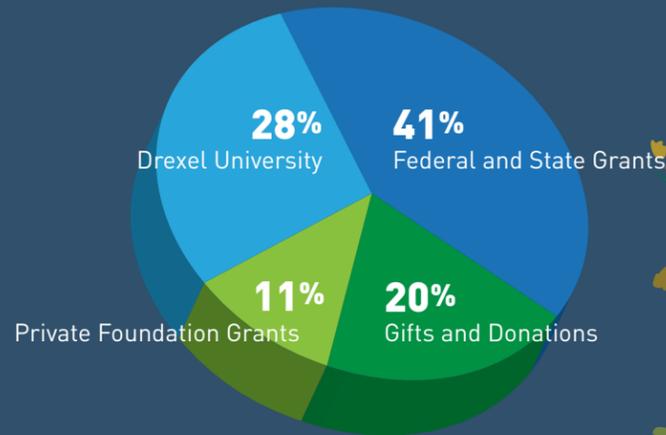
By comparing birth records over a period of nine years, research published in *Pediatrics* by Drexel researchers found that the children of mothers who took a certain asthma medication during pregnancy faced an elevated risk of being diagnosed with autism spectrum disorder.

NPR

Work done by the Life Course Outcomes Research Program on the National Autism Indicators Report was featured on *On Point* and the Diane Rehm Show last year.

FUNDING, GRANTS AND GIFTS

INSTITUTE FUNDING 2012-16



TOP FIVE GRANTS

The A.J. Drexel Autism Institute has attracted a number of major grants in a short period of time.

\$14.3M grant to Dr. Craig Newschaffer from the National Institute of Environmental Health, the National Institute of Mental Health, the National Institute of Child Health and Human Development, and the National Institute of Neurological Disorders and Stroke for the EARLI project.

\$3.6M anonymous foundation grant to Dr. Paul Shattuck for the Drexel Transition Pathways Initiative project.

\$3M grant to Dr. Diana Robins from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) for her project titled, "Early Detection of Autism Spectrum Disorder."

\$2.5M to Dr. Craig Newschaffer to work with colleagues at Florida State University on a project that is "Mobilizing Community Systems to Engage Families in Early ASD Detection and Services."

\$910k grant to Dr. Craig Newschaffer from Autism Speaks to support a 15-month project titled, "Concluding Follow-up of Families Enrolled in the EARLI Cohort."

THANK YOU

On behalf of the faculty and staff of the A.J. Drexel Autism Institute, we would like to thank our donors and funders who have contributed to the institute since its inception. Your generosity has helped us create a one-of-a-kind public health research institute focused on advancing our knowledge of autism. We are tremendously grateful for your support.

FEDERAL SPONSORS

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 - National Institute of Environmental Health Sciences
 - National Institute of Mental Health
 - National Institute of Neurological Disorders
 - National Science Foundation
- Department of Defense
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- Health Resources and Services Administration

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- Autism Science Foundation
- Autism Speaks
- Charles and Barbara Close Foundation
- John Templeton Foundation
- Lurie Family Foundation
- Major Anonymous Donor

We would also like to thank individual donors for their support.

SMALL GIFTS MAKE A BIG DIFFERENCE

Our new microfunding website gives friends of the A.J. Drexel Autism Institute the opportunity to crowdfund initiatives that are special to them. Please consider contributing to our ongoing projects designed to benefit the communities we serve.

drexel.edu/AutismInstitute/Giving



We achieve great things with your support. For more information or to make a gift, please contact:

Meredith Bloom • Project Manager, Philanthropic Initiatives • 215.571.3204 • Mhb54@drexel.edu



DREXEL UNIVERSITY

A.J. Drexel Autism Institute

3020 Market Street, Suite 560, Philadelphia, Pa. 19104

drexel.edu/autism 215.571.3401



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Welcome Area

During Non-Reception Hours
Please Proceed to Suite 560