A Message From the Director — A Decade of Impact

I am excited to share that the Lurie Center for Autism recently began its tenth year! We are deeply grateful to you, our loyal supporters and friends, and the Nancy Lurie Marks Family Foundation for your dedicated partnership. Our primary goal since the center’s inception has been to provide lifelong, multidisciplinary clinical care for individuals with autism spectrum disorder (ASD) and their families. We are clearly positioned as the leader in the field, and clinical and scientific progress must and will continue.

Since 2009, we have experienced a 225% increase in the number of patient visits we provide per year. The complexity of clinical presentations and associated medical co-morbidities continues to increase among the patients we serve. I am very proud of the breadth of expertise of our dedicated clinical team spanning nine disciplines, working together to provide the best, personalized care. Additionally, by integrating Spaulding Outpatient Center’s therapeutic offerings and the Aspire Program’s focus on improving social-communication and life-skills, we are ensuring that the Lurie Center can continue to offer comprehensive care across a lifetime.

A key aspect of our ability to provide the best, individualized treatment is our Patient Navigator for Autism and Developmental Disorders Program, led by Karen Turner, OT. Our team works with colleagues at Mass General’s main campus and in satellite locations to accommodate individuals with ASD and other disabilities in outpatient and inpatient medical care settings. The goal is to create a care plan that is unique to each individual patient’s clinical and personal needs. Hospitals from around the country have asked us to consult with them to develop a similar program at their institutions. Highlighted within these pages is a shining example of our team’s excellence in action.

I am delighted that we have continually been able to expand the reach of the Lurie Center beyond the New England region. Last year we evaluated and cared for patients from 26 of the 50 states, and we saw patients and families from 15 countries outside the United States, including China, Chile, Brazil and the United Kingdom (U.K.). Our telecommunications systems allow us to provide follow-up care to these patients and families via web-based visits. We have shared on pages 3 and 4 a special collaboration in the U.K. made possible by Sarah Yamini and her husband, Malik Dahlan. We look forward to working with more centers and countries around the globe to ensure all those with autism receive necessary care.

In addition to a significant expansion of our clinical services, our educational offerings now include a multitude of learners, from patients, parents and other caregivers to policy makers, students, trainees and professional colleagues. For parents, we provide workshops on the information needed when a young child is newly diagnosed with ASD, on the guardianship process and on behavior management.
Our specialized training also ensures that the next generation of caregivers receive in-depth exposure to the diagnosis and treatment of patients with autism, including a one-month elective for medical students — from Harvard and elsewhere. Importantly, every Pediatrics resident at MassGeneral Hospital for Children has a rotation in developmental behavioral pediatrics at the Lurie Center, and we have child and adolescent psychiatry fellows from not only MGH, but also Cambridge Health Alliance and Boston Children’s Hospital that rotate regularly at the Lurie Center. We also host post-doctoral neuropsychology fellows each year. Funding for research in ASD at the Lurie Center has increased substantially over the past decade. We conduct research on the interactions of the brain and immune systems during development and how this may go awry in those with ASD. We are grateful to Bob and Donna Landreth for their continued and generous support of this work.

Our clinical research portfolio includes: the development of safer and more effective medications for interfering symptoms like aggression, self-injury, anxiety and sleep disturbance; abnormalities in the gastrointestinal tract in people with ASD; the process of impaired bone mineralization in some children and adolescents with ASD; teaching parents how to safely manage symptoms of aggression and irritability displayed by their children at home and in the community; and using advanced technology in individual therapeutic sessions to help adolescents with ASD navigate social challenges in their day-to-day lives.

These are but a few of the efforts and accomplishments of the Lurie Center providers and staff since the center’s inception. Every day, there is tremendous excitement and energy because we all enjoy helping patients and their family members with the challenges they are facing, educating the next generation of clinicians and scientists, and conducting research to determine the causes of autism and develop more effective treatment interventions.

None of these great achievements over our first nine years would have happened without you. Despite the success of the Lurie Center, there is a stark reality that we all face. Reimbursement for patient care from insurance companies and state and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving and federal funding agencies is insufficient. We are dependent on philanthropy to close the clinical gap. Your generosity allows us to devote time to education, mentoring, research, and new initiatives — that are aimed squarely at improving...
After a couple of referrals in the U.K. didn’t result in a diagnosis, the family reached out to Dr. McDougle. An intensive week of appointments with him and other specialists was scheduled. On the last day, all the specialists gathered in a room with them to present the diagnosis and treatment plan.

“There was a lot of hand holding that week — and shock at hearing the diagnosis,” Ms. Yamani recalls.

Reports about Hamza, now seven years of age, are exchanged regularly between the London and Lurie teams and the family returns to Boston for his yearly evaluation.

“It would have been a disaster for him,” she says, “I don’t think without an early diagnosis and intervention programs, he would be the happy, social child he is today.”

The couple had to build their own team when they returned to London as nothing like the Lurie Center’s approach existed there. Determined to change that, they initiated the Autism Center of Excellence in the U.K., a transatlantic partnership with the Lurie Center and Mass General. Ms. Yamini’s goal is to bring the Lurie model of care to the U.K. and increase awareness about the importance of early diagnosis and intervention.

Dr. Kingsbury is currently examining whether events near birth modify inflammation within the brain and gastrointestinal disturbances, which can correlate with the severity of behavioral symptoms. Interestingly, individuals with autism often have significant gastrointestinal disturbances, which can correlate with the severity of behavioral symptoms.

Prior to joining the Lurie Center, Dr. Kingsbury was a faculty member in the Biology and Neuroscience Programs at Indiana University where she led a social behavior laboratory that studied how hormones in the brain, such as oxytocin, regulate social interactions and social anxiety. Dr. Kingsbury’s previous work also revealed how variation in brain circuits produces individual and sex differences in social behavior. She conducted postdoctoral work at the Scripps Institute for Childhood and Neglected Diseases in San Diego, CA, exploring how changes in the embryonic environment can shift the trajectory of brain development, producing alterations in brain structure and brain circuitry as individuals mature.

In early 2017, the Lurie Center for Autism was pleased to welcome Marcy Kingsbury, PhD, to its growing team of researchers. Dr. Kingsbury is a developmental neuroscientist whose expertise is the study of social behaviors, and in particular, social affiliation, which is the willingness to approach and engage in social interactions.

Meet the Experts: An Evening of Dialogue

Each spring, the Lurie Center opens its doors to parents and caregivers the opportunity to network and learn from each other. This annual educational event also offers parents and caregivers the opportunity to network and learn from each other.

Dr. Marcy Kingsbury

As part of the Lurie Center for Autism, Dr. Kingsbury studies interactions between the brain, the gut and the immune system during development, and how these interactions shape our overall health. It is becoming increasingly recognized that appropriate communication between these systems within the body gives rise to normal social behavior and cognition whereas lack of healthy communication between these systems can predispose individuals to disease.

An examination of the Gut-Brain Connection in Autism

As oxytocin is a protective molecule for the developing brain, her lab is adjacent to that of Dr. Alessio Fasano, a mucosal immunology specialist, allowing for unique collaborations to study gut-brain immune interactions, the microbiota axis, and mechanisms underlying neurodevelopmental disorders.
Lurie Center for Autism by the Numbers

Patient Visits: 2009 vs 2018
The Lurie Center has nearly tripled the number of patient visits since it was created in 2009.

<table>
<thead>
<tr>
<th>Year</th>
<th>Patient Visits</th>
<th>Individuals</th>
</tr>
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<tbody>
<tr>
<td>2009</td>
<td>2,482</td>
<td>1,322</td>
</tr>
<tr>
<td>2018</td>
<td>8,076</td>
<td>2,543</td>
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Increase in Adult Patients
The Lurie Center established its adult program in 2009.

- **932%**
  - Since 2009
- Last year, each adult patient on average visited the Center more than three times.

Visits by Discipline
The Lurie Center’s multidisciplinary approach ensures that patients receive the best possible care to meet their physical and psychosocial needs.

Increase in Research
The Lurie Center’s research productivity and volume continues to grow.

- **700%**
  - Since 2009

Lurie Center’s Expanding Patient Footprint
Patients come from across the country and around the world to receive the Lurie Center’s specialized care and treatment.

Lurie Center Operational Expenses and Income
The Lurie Center has a balanced mix of expenses and revenue. Still each patient visit requires at least a $250 philanthropic subsidy, as reimbursements for care do not cover the full complement of medical services.
The Potential of Affinity Therapy

"Affinity therapy" is a term coined by journalist Ron Suskind, creator of the technology known as Sidekicks, for kids, like his son, with autism. Children with autism spectrum disorder (ASD) often have a favored activity or fixation traditionally known as a "restricted interest," a preoccupation that may get in the way of other kinds of learning and communication. Mr. Suskind is among a growing number of parents and researchers who prefer to view these interests less as restrictive areas of focus and more as passions — or "affinities."

"Powerful interests, or affinities, can and do help people on the spectrum make social, emotional, and situational sense of the world, just as the rest of us rely on our passions to bring joy, relieve anxiety, know ourselves and engage with others," Mr. Suskind says. "Jamie has experienced this firsthand, and his support for research endeavors that will validate the experiences of people on the spectrum will be a step forward in the growing field of affinity research."

"Many therapists and parents really respond to the idea of seeing affinities as windows of opportunity to get into their child's world," says Kirstin Birtwell, PhD, staff psychologist at the Lurie Center for Autism. "Many therapists and parents really respond to the idea of seeing affinities as windows of opportunity to get into their child's world," says Kirstin Birtwell, PhD, staff psychologist at the Lurie Center.

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Now, 17, Jamie is more passionate than ever about helping people with ASD through technology. He recently met Dr. Birtwell at the Lurie Center, an experience he calls "exhilarating."

"Like me, she believes that technology can have a life-changing, transformative effect, and can empower and improve the lives of everyone affected by ASD," he says.

Looking Forward and Giving Back

"It's admirable what Jamie is choosing to do with his time," Dr. Birtwell says. "It's so refreshing to sit with someone so enthusiastic and motivated. I saw the light inside of him beam when he talked about the work being done, and what could be done."

For Jamie, it all comes back to the fact that autistic people deserve support and tangible help here and now. "I consider myself very fortunate, it's my way of giving back, of counting my blessings," he says. "My wonderful mentors, Drs. Leslie Fang and Gene Beresin, both cheered me on and insisted that there is no minimum age when it comes to doing good!"

To participate in this study or learn about other current opportunities, please email LurieCenterResearchPartners.org.

Game On for Autism Research

Researchers at the Lurie Center for Autism are exploring how commercial technologies might help children with autism communicate. The project is being supported by Game On For Autism Research (GoFAR), a non-profit founded by impassioned teenager Jamie Menhall from BU Academy High School.

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During an internship at a treatment center, Jamie realized that many of the patients shared his passion for video-games. He was surprised by how focused many kids were when playing Aurtcraft (Minecraft for people with autism). To him, it was a revelation: patients were engaged, touching, tapping and swiping screens, drawing and building digital structures with other players.

"I could sense pride and joy beaming from the children as their efforts were admired and reinforced," Jamie says. Inspired by this epiphany, Jamie began to research how games and touchscreen technology were being used to help autistic patients communicate. He was excited by the anecdotal evidence he found, but also surprised at the lack of science to back it up. The solution, he believed, was more targeted funding for inquiry into truly transformative, affinity-based technologies for ASD.

To date, GoFAR has raised money from private individuals, non-profit donors such as The Endicott Family Charitable Fund, and corporate sponsors such as Herb Chambers.

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The Lurie Center is grateful for the partnership of hospital colleagues who share our commitment to providing individuals with autism the best possible medical care. We also appreciate the Ruderman Family Foundation and the WITH Foundation (Working for Inclusive and Transformative Healthcare) for supporting Karen Turner, OT, and her role as Patient Navigator for Autism and Developmental Disorders at MGH.

MGH Champions for Autism Team Recognized

Undergoing a medical procedure can be frightening for anyone. For a patient with autism, it can be even more daunting. Recently, many groups across Mass General came together to help an extremely anxious, minimally verbal adult with autism get an MRI study. For weeks, the plan was thoughtfully organized by Karen Turner, an occupational therapist and MGH Patient Navigator for Autism and Developmental Disorders. Teams from radiology, security, disability services, anesthesia, perioperative services and the Lurie Center coordinated their efforts.

The multidisciplinary team is being recognized by Peter L. Slavin, MD, Mass General president, and presented with an Excellence in Action Award. This award honors employees for going above and beyond in providing extraordinary patient care and service.

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For Jamie, it all comes back to the fact that autistic people deserve support and tangible help here and now. "I consider myself very fortunate, it's my way of giving back, of counting my blessings," he says. "My wonderful mentors, Drs. Leslie Fang and Gene Beresin, both cheered me on and insisted that there is no minimum age when it comes to doing good!"

The two discussed Dr. Birtwell's affinity-based research, and how the project's data can pave the way for developing an understanding of who benefits from Sidekicks technology — and how best to get it into families' hands as soon as possible.
Lurie Center 2018 Events Recap

This year, several generous friends, volunteers, and donors hosted a number of community and educational events to raise much-needed awareness and philanthropic support for the Lurie Center for Autism. The proceeds from these efforts leveraged a generous matching contribution from the Nancy Lurie Marks Family Foundation.

Piece by Piece Walkathon

When Alexis Campbell, a senior at Oliver Ames High School in North Easton, MA, was tasked to choose a topic for her senior project, she knew she wanted to create one that fully captured the multi-faceted nature of ASD. After gaining valuable knowledge from Lurie Center staff on research, education, clinical treatment and personal care of patients with autism, she then hit the ground running on planning the Piece By Piece Walkathon. In addition to raising more than $4,000 for the Lurie Center, Alexis also raised awareness in the community, as each walkathon participant had to find the 12 facts hidden around the route and share at the end one thing they learned about autism.

Full Court Charity Challenge

In its 19th consecutive year, the Full Court Charity Challenge raised nearly $80,000 for the Lurie Center for Autism. Once again, devoted parent and Lurie Leadership Council member Bob Forlenza spearheaded the all-day basketball tournament with 24 teams and more than 200 players. Collegiate athletes, former semi-pros, and weekend warriors alike came together to raise critical funds for the Lurie Center’s family resource services. The event also supports Nashoba Learning Group.

Love for Lurie

Bowties were in abundance at this year’s Love for Lurie fundraiser! Hosted once again by Lurie Leadership Council members and parents Lizzy and Chris Matteini, the third annual community fundraiser was held on April 7 at the Barking Crab restaurant. Una and Amit Basak and Melissa and Mike Freni served on the host committee. More than 150 friends and family — donning creative bowtie — raised nearly $40,000 in donations for clinical support of the Center.

New Balance Falmouth Road Race

For the 4th year in a row, the Lurie Center for Autism was selected as an official New Balance Falmouth Road Race charity organization. On August 19, ten runners raced along the scenic 7-mile, oceanside course from Woods Hole to Falmouth Heights to raise autism awareness and funding for the Lurie Center’s Family Resource team. This year, devoted volunteer Tracey Turgeon led the runners to raise nearly $10,000.

Double your Donation

Thanks to a generous challenge grant put forward by the Nancy Lurie Marks Family Foundation, every dollar raised for clinical operations will be matched, essentially doubling the impact of each contribution.

Supporting the Lurie Center

The Lurie Center relies heavily on the generosity of families and friends to provide its world-leading, multidisciplinary care for people with autism. There are many ways to support the Lurie Center.

Want to host an event or run a race to benefit the Lurie Center and help patients and families with autism? Visit https://giving.massgeneral.org/crowdfunding-community-fundraising/ today!

To make a gift today, please visit our website: https://giving.massgeneral.org/donate/lurie-center/

Boston Marathon

Leadership Council member Mike Freni ran his 11th Boston Marathon in support of the Lurie Center. This year’s race was one runners won’t forget! A nor’easter plummeted New England and rendered a very cold and wet race day. Despite these challenges, Mike, joined by his brothers, Rob and Chris of Joey’s Team, completed the race and raised more than $16,000 to fund clinical support services. For Mike, running Boston each year provides a unique opportunity to raise autism awareness, and to support the multidisciplinary clinical offerings at the Lurie Center. As the father of a child who is treated at the center, running hundreds of miles over the last decade in honor of his son has taken on a very special meaning for Mike and his family.
Lurie Center for Autism

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Boston, MA 02114-2548

Join us
from 6:30-7:30 pm for a presentation & discussion
Registration is Required
Email: LurieCenter@partners.org
Call: 781-860-1700

The Lurie Center presents

December 11, 2018 at 4pm
LURIE LAND PARTY FOR PATIENTS AND FAMILIES

January 16, 2019
DISCLOSURE AND ASD: HOW DO YOU TELL YOUR CHILD, FAMILY, AND OTHERS?

February 13, 2019
PERSPECTIVE OF YOUNG ADULTS WITH ASD: LEARN FROM THE EXPERTS!
Scott McLeod, PhD - Facilitator

March 13, 2019
UPDATES ON LURIE RESEARCH INITIATIVES

April 24, 2019 at 6pm
MEET THE EXPERTS - AN EVENING OF DIALOGUE

May 15, 2019
MANAGING AGGRESSION AT HOME: UPDATES & TIPS FROM PARENT CPI TRAINING RESEARCH
Nicole Simon, EdM, LABA, BCBA

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