A Message From the Director

One of the most exciting and rewarding aspects of my role as Director of the Lurie Center for Autism has been leading the collaborative approach that our multi-disciplinary team uses to understand and to treat autism spectrum disorder (ASD). With the growth over the past year of our pre-clinical research program under Director of Research, Staci Bilbo, PhD, and the expanded collaboration between our clinicians and scientists, I believe that we are uniquely poised to address the causes and treatment of ASD.

For many years, ASD was considered a group of childhood-onset disorders that resulted from abnormalities in the developing brain. While we still believe that the brain is very much involved, it is becoming increasingly clear that many other areas of the body are also affected. For example, a high percentage of our patients have recurrent ear infections during their early years. Many also have significant gastrointestinal disorders and struggle with seasonal allergies, and at times asthma. Moreover, researchers at the Lurie Center and Massachusetts General Hospital have recently discovered that many adolescent boys with ASD have abnormal bone mineralization, which may place them at increased risk for fractures. This increased risk may be related to insufficient diet and reduced physical activity.

To address the many medical problems that can affect persons with ASD, the Lurie Center has providers across multiple disciplines. Being co-located in one building allows us to communicate together as a team, ensuring we are providing the best possible care to each of our patients. Our collaborative approach is also influencing our research initiatives.

When Dr. Bilbo joined the Lurie Center for Autism as Director of Research, I shared that she is considered the leading expert in the way the nervous system and immune system interact during normal and abnormal brain development. Her team in the Charlestown Navy Yard is already generating important data related to abnormal brain...
development in ASD. Like the approach of our clinical team, Dr. Bilbo’s lab is also investigating abnormalities in other organ systems - like the gut - in animal models of ASD. Increasing evidence is pointing to the importance of the gut-brain axis in the pathophysiology of at least a subset of individuals with ASD, and Dr. Bilbo and her team are leading the way in these investigations.

To augment our multidisciplinary approach to clinical care and research, both of our teams in Lexington and Charlestown have separate weekly educational conferences. About six months ago, Dr. Bilbo and I began integrating the discussions occurring in the clinical and research settings, respectively. Now, once a month, a clinician from the Lurie Center presents to the researchers at Dr. Bilbo’s lab, and a researcher from Dr. Bilbo’s lab presents to the clinicians at the Lurie Center. These cross-cutting presentations have been received with tremendous enthusiasm, provided new knowledge to both groups and resulted in translational “bench to bedside” research projects that span the pre-clinical and clinical arms of the Lurie Center. We are not aware of other institutions anywhere that have taken advantage of this unique approach to “translational education.”

I look forward to sharing updates about the clinical, educational and research initiatives that come as a result of this collaborative approach.

Sincerely,

Christopher J. McDougle, MD
Director, Lurie Center for Autism
Mass General, MassGeneral Hospital for Children
Nancy Lurie Marks Professor, Harvard Medical School

London Family Looks to Emulate the Lurie Center’s Model in the UK and Beyond

When Malik Dahlan and Sarah Yamani noticed their third son, Hamza, was not progressing at the same rate as his older brothers, they were on a quest to find answers and resources. Soon they were pointed to the Lurie Center for Autism at Mass General where their son received a comprehensive evaluation and a diagnosis of autism as well as a plan to act upon. Empowered with this diagnosis, and knowing that early intervention was key to success, they returned home to London only to find committed individuals up against a fragmented healthcare system. The family was in a fortunate position however, and able to put the pieces together; today Hamza is thriving.

Their family’s journey has inspired Malik and Sarah to spearhead an international partnership, the Autism Center of Excellence (ACE), aimed at creating a more seamless, integrated system of care for all children and families who are struggling with autism. With a philanthropic investment from the family, the Lurie Center is utilizing telehealth, education and research collaborations to extend its expertise to an international audience. Institutions such as Imperial College London and Cambridge University, among other universities in the UK, are all keen to collaborate and make this transatlantic initiative a reality.
“As a child with autism grows into an adult with autism, there are many unknowns that cause worry and concern. However, knowing that the Lurie Center is available to provide care for your family member lessens such worries. We will be forever grateful for everything the Lurie Center has done for our family.”

Parent of a young adult

The Lurie Center is a unique and precious gem. It took 40 some years of being a pediatrician to find a position as satisfying as my current one. The Lurie Center brings together professionals with intellectual curiosity, devotion to patients and their families, respect for each other and a commitment to expand knowledge, treatment options and support for children and adults with autism spectrum disorder.”

Lurie Center Physician

We hope your experience with the Lurie Center reflects our commitment to compassionate, personalized care. We are only able to provide this level of comprehensive care thanks to the support of families and friends like you, as health insurance reimbursements cover less than half of our clinical costs. The balance is paid for by philanthropy – more than $2 million dollars per year. To ensure the Center’s continued sustainability, the Nancy Lurie Marks Family Foundation has issued a challenge; they will match each dollar raised for clinical services, $1 for $1.

Your participation in this remarkable challenge will double the impact and help ensure that the Lurie Center remains available to families and patients with autism for generations to come.
New Physician at the Lurie Center Brings Personal Perspective

In August, the Lurie Center for Autism welcomed a new physician to its growing team of specialists. **Sylvia Fogel, MD,** is a clinical psychiatrist who specializes in working with parents of children with special needs.

Before moving to Massachusetts, Dr. Fogel had a busy private practice in New York City where she specialized in psychotherapy, psychoanalysis and perinatal psychiatry. Dr. Fogel was an Assistant Professor of Clinical Psychiatry at Columbia University College of Physicians and Surgeons until 2017, where she taught and supervised residents and fellows and educated psychoanalytic candidates.

Parents of children with autism spectrum disorder and other special needs are faced with enormous challenges every single day. Research now suggests that these demands place parents at an increased risk for a range of health issues stemming from chronic stress. This, in turn, will directly affect their ability to keep meeting those challenges.

Her work also holds personal relevance. Dr. Fogel has three children, one of whom, her son, age 9, has severe autism. Her experiences inform her work with parents.

In October, Dr. Fogel launched a weekly parental support group. Participants gain support, network with other parents, and learn simple, evidence-based techniques for better self-care. The sessions can help improve mood, regulate stress and more while still managing the modern demands of a busy family. In early 2018, the Lurie Center will also begin offering two additional support group options facilitated by Dr. Fogel - one specifically for couples and one for fathers. Parents who are new to the Lurie Center are welcome to register after an initial in-person consultation with Dr. Fogel.

“"The level of stress parents with a child on the spectrum face is unparalleled and often vastly underestimated. It can pose significant challenges to both their health and personal well-being. I am pleased to join the Lurie Center to provide much needed professional support to parents and families."

*Sylvia Fogel, MD*

Dr. Fogel received her BS in human development and family studies from Cornell University in 1994. She received an MD from Cornell University Medical College in 1999 and then completed a residency in psychiatry at Columbia University and the New York State Psychiatric Institute in 2003. Dr. Fogel subsequently went on to study clinical psychoanalysis and psychoanalytic theory at the Columbia University Center for Psychoanalytic Training and Research and received a certificate in psychoanalytic medicine in 2010.

Over the years, Dr. Fogel has had increasing opportunity to work with the parents of special needs children and has extensive experience with issues unique to this community. Dr. Fogel also developed an increasing interest in functional and holistic medicine. She became board certified by the American Board of Integrative and Holistic Medicine in 2014.

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**Welcome, Dr. Fogel, to MassGeneral Hospital for Children and the Lurie Center for Autism!**

www.luriecenter.org
Harnessing research advances to impact ASD

Determining the role of the immune system and inflammation as they relate to the pathophysiology of autism spectrum disorder (ASD) represents a signature research focus of the Lurie Center for Autism. To date, three primary studies – underwritten largely through a generous donation from Robert and Donna Landreth – have been initiated.

After recognizing that a significant number of patients had family members with autoimmune disorders such as multiple sclerosis, lupus or rheumatoid arthritis, the Lurie Center began collecting detailed family histories to determine the prevalence of autoimmune disorders in first- and second-degree relatives of people with ASD. They have also been recruiting and characterizing subjects with ASD and healthy controls for participation in brain imaging research to evaluate inflammation in the brain.

The laboratory of William Carlezon, PhD, at McLean Hospital has developed a mouse model of ASD to determine whether exposure to an infection during pregnancy leads to offspring developing the core symptoms of autism. This research has shown that mouse pups born to mothers given a synthetic virus during pregnancy who then receive an injection of bacteria shortly after birth, are more likely than those given a placebo to show reduced vocalization and social interaction, as well as increased anxiety and seizure activity. Interestingly, male mice seem to be affected by the pre- and post-natal immune challenges, while the female mice appear to be protected from the abnormalities by unidentified factors.

Research directed by Jacob Hooker, PhD, at the Martinos Center for Biomedical Imaging has generated surprising results. Contrary to the initial hypothesis, using a unique combined magnetic resonance imaging (MRI)/positron emission tomography (PET) brain scanner, Dr. Hooker and his group found that a brain marker for immune activation was significantly reduced in adult males with ASD compared to that of healthy adult male controls (see Figure).

Additional research is underway to explain these unanticipated findings. Based in part on the results from Dr. Carlezon’s research showing significant sex differences in the way mice respond to immune challenges, the team is now enrolling adult females with ASD into the MRI/PET brain imaging study. If we can identify significant differences between males and females with ASD in their ability to generate immune activation, the findings may contribute to a better understanding of the male bias in ASD prevalence.

With her appointment as Director of Research at the Lurie Center in 2016, Dr. Staci Bilbo has added complementary research ideas that are accelerating our ability to better understand the impaired immune/inflammatory processes that may underlie a subtype of ASD. Our goal is to translate that knowledge into effective treatments and, one day, preventive strategies.

Ultimately, the Lurie Center aims to understand and treat the biological underpinnings and potential root causes of ASD, and with each new finding comes new questions which move medicine closer to that goal. Philanthropy has been, and will remain, essential to keeping the avenues of scientific investigation open. 

Clinical research cannot happen without the participation of patients, families and individuals in the community.

Email LurieCenterResearch@partners.org to learn more about current opportunities.
**Lurie Center for Autism by the Numbers**

**Patient Visits: 2009 vs 2017**

The Lurie Center has nearly tripled the number of patient visits since it was created in 2009.

- **2009**
  - 2,482 Patient Visits
  - 1,322 Individuals

- **2017**
  - 7,354 Patient Visits
  - 2,214 Individuals

**Increase in Adult Patients**

The Lurie Center established its adult program in 2009.

- **214%** Since 2009

Last year, each adult patient on average visited the Center more than three times.

**Visits by Discipline**

The Lurie Center’s multi-disciplinary approach ensures that patients receive the best possible care to meet their physical and psychosocial needs.

**Patient Population at a Glance**

- **0 - 5 years** 14%
- **6 - 12 years** 37%
- **13 - 17 years** 19%
- **Adults** 30%

www.luriecenter.org
Medical expenses are, on average, 4 - 6 times greater for those with an autism spectrum disorder than for those individuals without ASD.

Philanthropy continues to play a vitally important role in supporting the Lurie Center - accounting for more than **50% of operational income**.
Mentoring the Best and the Brightest

Education on autism spectrum disorder (ASD) and related neurodevelopmental disorders – whether focused on clinicians, parents, researchers or individuals with ASD themselves – is a primary mission of the Lurie Center for Autism. The Center is especially focused on training the “next generation” of clinician-scientists with its evolving and unique mentorship program.

Dr. McDougle first created the Lexington-based mentoring program for junior faculty clinicians and researchers in 2013. The group was designed to foster intellectual curiosity, collaboration, professional development, and advancement of academic and research careers. Over the past four years, this mentoring group has grown and expanded to allow unique and exceptionally important collaborations among clinical and research faculty.

Angelman Syndrome Clinic Expands Research and Clinical Services at the Lurie Center

With the support of the Angelman Syndrome Foundation (ASF), Mass General’s Angelman Syndrome Clinic has expanded its clinical services at the Lurie Center. The expanded program is led by neurologist Ron Thibert, DO, and psychiatrist, Christopher Keary, MD, in consultation with Christopher McDougle, MD, and Nicole Simon, EdM, BCBA.

Angelman syndrome is a rare genetic disorder which occurs in one in 15,000 live births. Individuals with Angelman syndrome experience developmental delay, lack of speech, seizures, walking and balance disorders, and typically exhibit a happy demeanor characterized by frequent smiling, laughter and excitability.

Since it was established in 2008, as one of the first Angelman syndrome specialty clinics in the country, the clinic has seen more than 250 patients. With access to multiple subspecialists and a variety of medical resources in one setting, the clinic – under the direction of Dr. Thibert – quickly became renowned for its expertise in seizure management.

Despite the “happy” demeanor often characterized by an Angelman syndrome diagnosis, families and clinicians have observed patients developing patterns of new and challenging behaviors, such as self-injury and aggression, as they got older. As the clinical team explored the possible root causes of these behaviors, they found that many patients were demonstrating symptoms of anxiety.

Dr. Keary is now leading an ASF-funded study aimed at defining the prevalence and nature of anxiety in Angelman syndrome. Data from this study will be a crucial first step in characterizing the condition and informing the development of diagnostic tools and interventions to treat anxiety and its related symptoms in this population. With an expanded clinical focus, Dr. Keary, Dr. McDougle and Nicole Simon are already translating findings into treatments that are making a real difference in the lives of patients and families.

If you are interested in learning more about the study, email LurieCenterResearch@partners.org.
Following Dr. Bilbo’s recruitment in 2016, she and Dr. McDougle soon recognized that the regular connection of her pre-clinical lab mentees to the comparable Lurie Center clinician mentees could create a novel training model for her students, post-doctoral fellows and junior faculty, while promoting the development of ASD research.

“Prior to coming to MGH, I was a faculty member at Duke University for 9 years. In all that time, I never once interacted with an individual with autism, despite attempting to model this disorder in animals. During my short time here at MGH, the creation of this fundamentally different training model has truly been transformative and extremely rewarding for me and for my team.”

Staci Bilbo, PhD

With two monthly meetings between pre-clinical and clinical faculty, in addition to the separate meetings of each mentoring group, all participants benefit. Clinical and pre-clinical faculty essentially “speak a different language,” and regular interaction allows both sides to practice presenting their findings in accessible terms, understandable to those without a science background or clinical training, and vice versa. Thus, each group gains valuable experience in communication and presentation.

The exchange also encourages a greater focus on the clinical relevance of the basic scientists’ work, helping them to refine their hypotheses and to design animal and other neurobiological experiments in a way that best serves and reflects the clinical population of people with ASD. Meanwhile, the clinicians gain opportunities to contribute to important basic science research and to remain up-to-date on the latest cutting-edge science around the biology underlying autism.

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Lurie Center 2017 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.

Full Court Charity Challenge
In its 18th consecutive year, the Full Court Charity Challenge raised more than $89,000 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
This year’s Love for Lurie fundraiser was a throwback to the ‘80s! Hosted once again by Lurie Leadership Council members and parents Lizzy and Chris Matteini, the second annual community fundraiser was held on April 1 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 – decked out in their best 1980s attire – raised nearly $40,000 in donations for clinical support for the Center.

Boston Marathon
Leadership Council member, Mike Freni, ran his 10th Boston Marathon in support of the Lurie Center. Joined by his brothers, Rob and Chris, Joey’s Team raised more than $10,000 to fund clinical support services. For Mike, running Boston each year provides a unique opportunity to raise autism awareness, and to support the multi-disciplinary 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.
Meet the Experts: An Evening of Dialogue
Each spring, the Lurie Center opens its doors to parents and caregivers who are eager to hear from world-leading autism experts, researchers, and MGH faculty on the latest clinical and scientific advances in autism at An Evening of Dialogue. This annual educational event also offers parents and caregivers the opportunity to network and learn from each other. More than 100 people attended this year’s Evening of Dialogue, which was held on April 25.

New Balance Falmouth Road Race
For the 3rd year in a row, the Lurie Center for Autism was selected as an official New Balance Falmouth Road Race charity organization. On August 20, thirteen 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 more than $20,000 – an increase of more than $3,000 over last year’s total.

Supporting the Lurie Center
The Lurie Center relies heavily on the generosity of families and friends to provide its world-leading, multi-disciplinary 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/

Double your Donation
Thanks to a generous challenge grant put forward by the Nancy Lurie Marks Family Foundation, every dollar raised for clinical operations in 2017 will be matched, essentially doubling the impact of each contribution.
Join us
the 3rd Wednesday of the month from 6:30-7:30 pm for a presentation & discussion

Registration is Required
Email: LurieCenter@partners.org
Call: 781-860-1700