By: Jennifer Nejman Bohonak

Jacob Hooker, PhD, the new scientific director at the Lurie Center for Autism at Massachusetts General Hospital, wants to build connections between the Lurie Center’s world-class clinical program and the greater Boston community of innovative science. He hopes this effort to work collaboratively will give people with autism spectrum disorder (ASD) more treatment options to manage their interfering symptoms. Today, medications can help, but none address the “core symptoms,” as Dr. Hooker describes them, such as the difficulty with social-communication experienced by people with ASD.

**Innovative Leadership**

For more than 10 years, the Lurie Center for Autism has been an international leader in patient care, advocacy and research to help children and adults with ASD and other developmental disorders. With its clinical and research base in Lexington, Mass., the Lurie Center offers a wide variety of services.

Dr. Hooker brings his experience as a neuroscientist at the Athinoula A. Martinos Center for Biomedical Imaging at Mass General, where he also studies autism, to his new role as the Lurie Center’s scientific director. Dr. Hooker is also the Lurie Family Professor in the Field of Autism Research at Harvard Medical School.

“My dual roles at the Martinos Center and Lurie Center are an example of how Mass General supports innovative approaches to research and large-scale collaboration,” Dr. Hooker says.

**Mapping the Future**

This year, Dr. Hooker and his team are working to create the Lurie Center ASD Science Atlas, a web-based visual platform. The platform will be open to researchers at other institutions and encourage idea-sharing, he says. Through the atlas, the team will work to connect scientific discovery in areas of brain research that share common underlying neuroscience with ASD. One example is to determine if there are connections to neuroinflammation that occurs in degenerative diseases, such as Alzheimer’s disease, Dr. Hooker says.

Dr. Hooker plans to recruit early-career faculty scientists and postdoctoral fellows to conduct, grow and connect the Lurie Center to biomedical research at MIT, the Broad Institute and biotechnology and pharmaceutical companies.

“My job is to develop a strategy for how we move autism science forward in a very meaningful way,” he says. “Ultimately, I want to see a tangible connection between the things that our research team can do and the patients we serve. Bold catalysis of breakthroughs in autism will start with philanthropy — there is no other path.”

*(Continued on page 3)*
A Message from the Director

Dear Friends, Patients, Families and Colleagues,

On behalf of everyone at the Lurie Center for Autism, thank you for your continued support and steadfast dedication to our mission as we continue to navigate the challenges presented by the pandemic. We gather strength by focusing on our work with devoted families and staff who are committed to helping individuals with autism spectrum disorder (ASD) develop throughout their lives to reach their desired maximum potential.

2021 marks my 10 year anniversary serving as the director of the Lurie Center for Autism at Massachusetts General Hospital. We have many things to celebrate as a community that I would like to highlight at this milestone:

- We have grown to become one of the largest and most comprehensive autism treatment programs in the country, conducting more than 77,000 medical appointments over the past 10 years. When I joined the Lurie Center, we were averaging about 6,000 medical appointments a year — last year we doubled that to more than 12,000.
- We now serve more adults with autism than any other program in the country. Over 46% of our visits last year were with individuals 18 years or older.
- We conduct research on the causes of ASD with the goal of developing safer and more effective treatments. One of our main areas of research explores the interaction of the brain and immune system during development and how their development may go awry in those with ASD.
- Another primary area of our research investigates what factors contribute to an individual with ASD remaining non-verbal to minimally verbal.
- For our research, we collaborate with other leading academic medical centers and institutions across Boston, including The Broad Institute, Massachusetts Institute of Technology, Boston Children’s Hospital, Brigham and Women’s Hospital, The Martinos Center for Brain Imaging and McLean Hospital. We also collaborate with institutions across the country.
- We publish our research in leading scientific journals to move the science forward. Over the last year more than 16 manuscripts were accepted for publication.
- We have recruited and retained 23 incredible physicians and psychologists who are devoted to caring for our patients and their families.
- Notably, we recently recruited the Lurie Center’s new scientific director Dr. Jacob Hooker, profiled on pages one and three.
- We continue to educate the next generation of medical providers so that all people with ASD are accepted, celebrated and can fully realize their life goals.
- We continue to provide care, both virtually and in clinic, for some of the most complex individuals with autism from across 40 states and 20 countries.

The Lurie Center for Autism was founded on philanthropy, thanks to the Nancy Lurie Marks Family Foundation. It is with enormous gratitude to our continued donors that the Lurie Center can provide world-renowned care. I have witnessed immense dedication as we have developed a community of philanthropic supporters who are passionate and determined. Our amazing supporters have played in charity basketball tournaments, run marathons, hosted special events and contributed their time, talent and resources to us. In my 10 years as director, we have received over $42,000,000 in donations from more than 5,000 individual gifts coming from 14 different countries. We simply could not do our work without you, our fearless supporters! Thank you for being important members of the Lurie Center community.

As you will see throughout this newsletter, we have a bright future with positive momentum in our missions of clinical care, research, education and advocacy. We will remain resilient as we adjust to the new normal of the pandemic and are grateful to have you with us as we continue our journey.

Sincerely,

Christopher J. McDougle, MD
Unveiling ASD Biology Thanks to Philanthropy

The Lurie Center for Autism was established with a transformational gift from Mrs. Nancy Lurie Marks and the Nancy Lurie Marks Family Foundation, which, since 2009, has invested more than $50 million to advance autism treatment and research. While the first decade focused on clinical expansion, in particular caring for the growing numbers of adults with autism, the emphasis now is on leveraging the clinical platform to advance innovative research. The foundation recently made a gift of $3.25 million to support this research expansion.

In 2013, Dr. Hooker was brought into autism research when Bob and Donna Landreth of Midland, Texas, made their first significant gift, inspired by their grandson, to study inflammation in the brain and its connection to ASD. The study the Landreths funded involved work at the Martinos Center, where Dr. Hooker and his team used neuroimaging of individuals with ASD to study microgli, which are non-neuron cells in the brain that are also part of the immune system. The team found microgli in males produced a very different signal than in females. The research, published in 2019, could further understanding of why autism affects four times more males than females.

The study used brain scans and was the first of its kind. The team developed ways for nonverbal patients to communicate with researchers during the scan to reduce anxiety. “Imaging gives us a window into the brain that is incredibly powerful and underleveraged,” Dr. Hooker says. “This is a big step. In future studies, we can think about how to intervene to lessen or prevent autism.”

An Eye Toward Future Research
Christopher J. McDougle, MD, director of the Lurie Center and the Nancy Lurie Marks Professor of Psychiatry at Harvard Medical School, says the team is excited to have Dr. Hooker lead. “He is one of the most talented, creative minds in the world, and, I am certain that, through his leadership, the Lurie Center will make critically important contributions to better understanding the causes of autism and developing more effective treatment interventions.”

Throughout his own career, philanthropy has also played an important role, Dr. Hooker says. Dr. Hooker was named a Phyllis and Jerome Lyle Rappaport MGH Research Scholar 2016-2021, and through the program, he was able to pursue bold research and secure additional funding.

Dr. Hooker says the pace of autism research in the years to come will continue to rely heavily on donor support.

“The investment of the Nancy Lurie Marks Family Foundation and the Landreths are helping us recruit talented people, solve problems and leverage additional money for bigger studies,” he says. “Without such transformational support, there is absolutely no way we could make a difference.”

To make a gift to support research at the Lurie Center for Autism, please contact the Development Office at 617-726-6853.
A new Lurie Center initiative led by Yamini Howe, MD, a developmental behavioral pediatrician, and Caitlin Ravichandran, PhD, a biostatistician and researcher, aims to increase access to care at the Lurie Center for diverse and underserved children who have been diagnosed with autism spectrum disorder (ASD). Early diagnosis and access to treatment are critical to improving outcomes for individuals with ASD, but feedback from pediatricians across the Mass General community health centers suggests that some of the most vulnerable pediatric patients at Mass General too often run into trouble accessing Lurie Center services.

Historically, Hispanic and non-White children are less likely to receive an early ASD diagnosis and therefore miss out on critical care in their first few years of life. To address these inequities in care, Drs. Howe and Ravichandran are partnering with Aisha James, MD, a pediatrician who works in the MGH Community Health Centers. Dr. James develops and manages the referral process so that challenges such as language barriers and transportation issues are resolved and ultimately ease access to the excellent care that the Lurie Center team provides. As part of this initiative, the team is also aiming to hire a community health worker who specializes in ASD. In the near future, this individual will support families through the complex process of accessing care at the Lurie Center and obtaining recommended services throughout Mass General.

Primary care physicians, especially those who care for adults with autism, are often hard to come by. Adults with autism have daily health care needs, but frequently struggle to access the care they need, in part because medical interactions can be challenging.

This year the Lurie Center has made strides to increase its impact by offering a new full time service. James Bath, MD, a board-certified family practitioner, will be offering comprehensive primary care exclusively for patients with autism and other neurodevelopmental disabilities beginning January 1, 2022.

As a parent of a child with autism, Dr. Bath understands that patients with autism and other neurodevelopmental disorders have unique needs. “When my son was diagnosed, we experienced the same fear and uncertainty that all parents feel at the time of a life-altering diagnosis. But along the way, we met knowledgeable and compassionate providers, teachers, and therapists who helped our son and helped us find our way. I hope to share what I have learned both personally and professionally with other families.”

Dr. Bath’s new schedule represents a significant increase in office hours and clinical coverage, which will go from two days per month to four days per week. Care will include routine check-ups and wellness visits, school and program physicals, sick visits and chronic disease management. He will also coordinate care and communicate with multispecialty teams to help patients and families navigate the complexities of the healthcare system. He is dedicated to offering compassionate, flexible and thorough care to each patient at every visit.

The Lurie Center for Autism understands the challenges its patients experience and is taking new steps to eliminate barriers to care. The Lurie Center team strongly believes that each unique individual deserves the opportunity to access the breadth and quality of services they need to reach their full potential, regardless of economic, social or ethnic background.
Targeted Education for Autism Across Medical Specialties

For more than a quarter of a century, the Nancy Lurie Marks Family Foundation (NLMFF) has supported organizations dedicated to helping people with autism lead fulfilling and rewarding lives. The Lurie Center for Autism is tremendously fortunate to be among the Foundation’s key partners and helps to advance the Foundation’s mission on multiple fronts.

This past May, Harvard Medical School’s (HMS) Office for External Education was awarded more than $2 million to launch phase two of Targeted Education for Autism Across Medical Specialties (TEAMS). This educational initiative aims to develop innovative trainings for clinicians, as well as patient and family resources to improve health care for all adults with ASD. Lurie Center staff and collaborators, including Dr. McDougle and Karen Turner, MS, OTR/L, an occupational therapist skilled in helping people with autism, among many others, played a key role in the pilot phase of the TEAMS project. They were also instrumental in connecting the program developers with Lurie Center patients and families. The Lurie Center’s support during the pilot program in 2018-2019 laid the groundwork for TEAMS phase two funding.

The TEAMS Program focuses on transitions from pediatric care to adult care across medical specialties, and across the lifespan. The goal with the TEAMS initiative is to support these life transitions, not only for patients and their families, but for the providers and health systems involved in the transition. The support TEAMS provides aims to ease transitions at these critical but manageable moments. This will inevitably have an outsized impact on the experience of care for people with autism as they age and as they require additional or more complex clinical services across medical specialties. By focusing on transitions, TEAMS offers the best opportunity for systemic change through scalable and practicable interventions.

In collaboration with the Lurie Center, TEAMS will focus on the key aspects of caring for adults with ASD so that each patient can be best supported through their care across medical specialties. The TEAMS educational program is made up of four modules and covers the basics of ASD, adults with ASD, preparing for and supporting transitions and best practices, strategies and tools for treating and supporting patients with ASD. To support this work Dr. McDougle will lead a team of clinical advisors from the Lurie Center, including James Bath, MD, Lisa A. Nowinski, PhD, Robyn P. Thom, MD and Karen Turner, to further collaborate with clinicians across Mass General and other HMS-affiliated hospitals.

Phase two of TEAMS also includes the development of a web-based portal featuring patient and family educational materials aimed at improving health care for adults with ASD. The portal will provide health information to people around the world through a variety of media to educate and support ASD patients and their families. Looking ahead, the TEAMS group hopes to launch live learning and leadership symposia activities and curate and adapt content for other audiences, particularly medical specialists who most often see patients with ASD.

All of these efforts directly align with the priorities of the Lurie Center and NLMFF, both of which emphasize improving health care experiences and access to medical services for individuals with autism across the life span and aim to foster a more comprehensive understanding of autism among clinicians.
Lurie Leadership Council Members Tell Us Why They Are Involved

“Dr. McDougle has changed the trajectory of our sons’ lives. They would not be living safely at home without his care and intervention. He, alongside Dr. Bath, Dr. Neumeyer, Dr. Kadzielski, Dr. Nowinski, Julie O’Brien and the countless nurses and staff members we have been in contact with over our 11 years at Lurie, enable us to support Anjan and Sachin to be their best and happiest selves.”

— UNA AND AMIT BASAK

“We volunteer for the Lurie Center because our family found support and direction when we were struggling the most—our son’s escalating behavioral problems at home and school and uncertainty about the future. The Lurie Center created a multi-pronged plan for us that improved the quality of our son’s life, and therefore our family life. Coming to the Lurie Center is like finding a home, a place where we belong and we will stay to weather any storm that may come throughout life.”

— DIRA AND DAVID CANNISTRARO

Ways to Give in Honor of Dr. McDougle’s Tenth Anniversary

- Make a one-time gift of $1,000 or 10 recurring monthly gifts of $100 through our secure website at https://giving.massgeneral.org/autismsupport or by check mailed to:
  Mass General Development Office
  125 Nashua Street, Suite 540
  Boston, MA 02114

- Set up a community fundraiser with a BeCause fundraising page for the Lurie Center.

- Give gifts of appreciated stocks, bonds or mutual funds directly to the Lurie Center. These gifts are exempt from capital gains taxes.

- Make a charitable swap by giving appreciated investments without changing your portfolio. With this option, donating appreciated assets creates TWO tax benefits. The tax deduction is the same size as a cash gift while allowing you to avoid paying a capital gains tax. With a charitable swap, you donate old shares of stock and immediately purchase new shares in the same company. Your portfolio doesn’t change, but the capital gain is removed.

- Anyone over the age of 72 can donate their Required Minimum Distribution (RMD) from their Individual Retirement Account directly to the Lurie Center with no tax consequences.

- Recommend a grant from an already established Donor Advised Fund or Family Foundation.

- Consider leaving a gift of any amount to the Lurie Center in your will, trust, retirement account or other long-term plan.

Double Your Donation

Thanks to a generous challenge grant from the Nancy Lurie Marks Family Foundation, every dollar you give for clinical care will be matched, and your impact will be doubled. Please give today and help individuals with ASD and their families thrive now.

Your Support is Critical

The Lurie Center relies on philanthropy from families like yours to provide high-quality clinical care, research, training and advocacy for people with ASD. Unfortunately, insurance reimbursements and government funding do not cover the full cost of the services the Lurie Center proudly delivers, and on average, the Center loses $684 per patient—which adds up to nearly $2 million per year. Contributions from families like yours are vital to keeping the Lurie Center’s mission alive and its doors open.

To learn more about how your gift can make a difference, contact Dominic Brodeur in the Mass General Development Office at dbrodeur1@mgh.harvard.edu or at (617) 726-6853.
Lurie Center Visits by Age

- **46%** Adults 18+
- **9%** Ages 5 and under
- **45%** Ages 6-17

Virtual Visits vs In-Person

- **1,505** In-person visits
- **10,564** Virtual visits

Number of Patients Seen

Anually 2009-2021

- **134%** Increase

Number of Patient Visits

2009-2021

- **386%** Increase
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<td>January 26, 2022</td>
<td>Parenting a Neurodiverse Gender Fluid Child - A Family’s Personal Journey</td>
<td>Elise Wulff, MEd and Shira Cohen</td>
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<td>February 16, 2022</td>
<td>The Truth About ABA - It’s Complicated!</td>
<td>Nicole Simon, EdM, LABA, BCBA and Kirstin Birtwell, PhD</td>
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<td>March 23, 2022</td>
<td>Research Innovations</td>
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<td>April 27, 2022</td>
<td>Catatonia - From Diagnosis to Treatment Options and Prognosis</td>
<td>Christopher J. McDougle, MD</td>
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<td>May 18, 2022</td>
<td>Dating on the Spectrum</td>
<td>Brett Mulder, PsyD and Alyssa Travers, PhD</td>
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<td>June 15, 2022</td>
<td>Creating Your Roadmap for the Transition to Adulthood</td>
<td>Renee Green, PhD and Julie O’Brien, LMHC</td>
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<td>July 20, 2022</td>
<td>The Important Role of Grandparents for Families with ASD</td>
<td>Scott McLeod, PhD</td>
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<td>August 17, 2022</td>
<td>ASD and Restricted Diets - Helping Your Child Stay Healthy</td>
<td>Dominica Nichols, PhD, RD, LDN and Sarah Kadzielski, MD</td>
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