The cover photo highlights a collage by artist John Williams whose remarkable work is now featured at the Lurie Center. John’s art has been recognized in many ways — a cover story for the magazine *Folk Art Messenger*, a feature article in the *Boston Globe*, the book *Drawing Autism* edited by Jill Mullin, and at many exhibits throughout New England and beyond.

John — an adult with autism spectrum disorder (ASD) — sees his work as a metaphor for his daily life. In an interview with *Folk Art Messenger* contributor Paul Yandura, John described his work: “The world is for me a chaotic place,” he said. “Thoughts and images swirl around endlessly in my head, making it hard to stay calm and focused. Art helps me live with autism by channeling my energy into creating new visions. I make order out of chaos by organizing many disparate elements into a unified and coherent image.”

Much of John’s work is focused on history, and he is meticulous about investigating so that his collages accurately represent the subject. He writes on his website, “I spend significant time researching my subjects to learn about them and their historical surroundings. By marryng my artistic vision with my passion for history, I seek to present a new perspective on history.”

Seeing John’s work in person is necessary to fully appreciate the details and nuances of his art. After his intense investigation of the subject, there is a laborious process that uses hundreds of small pieces of cut paper to create the likeness of his subject matter. In effect, John “paints with paper.”

The Lurie Center would like to display the work of other individuals with autism spectrum disorders throughout the Lurie Center. We have been fortunate to be able to share the work of John Williams and Billy Megargel (see www.wmmartgallery.com ) with our visitors.

Please call us at 781.860.1739 or email us at luriecenter@partners.org if you would like to display art at the Lurie Center.
Twenty-five years ago autism was considered a rare disorder with a prevalence of 2-4 per 10,000. In 2008, the prevalence in the U.S. was reported at 1 in 88 children. Recently the Centers for Disease Control reported that the prevalence of autism spectrum disorder has risen to 1 in 68 children.

These numbers indicate that parents will be seeking diagnostic clarification for many more children, and that over the past 15 years, more children with ASD are aging out of schools where they often stay until they turn 22. Where will the increasingly large number of adults with ASD live, work, go to school and receive health care? Are we prepared for this as a society?

In addition to addressing the challenges of daily living, the medical community never anticipated this unprecedented spike in the prevalence of ASD. Physicians and hospital systems are not yet braced or prepared to take on this urgent responsibility. Addressing this tremendous shortage of adequately trained medical providers will require significant changes in the way that medical and other professional students are educated. The care of individuals with developmental disorders, like ASD, will likely need to become a medical specialty in its own right.

While we struggle with the day-to-day realities of how to provide adults with ASD the basic necessities of life, we also need to determine what is causing this surge in the number of individuals being diagnosed with ASD. While genetic causes can be
identified in up to 15-20% of persons with ASD, the etiology of the syndrome remains unknown — 80% of individuals are considered to have “idiopathic” autism. More resources need to be directed toward research if we are going to be able to find the causes of the various subtypes of autism. Without such a significant investment, the prevalence rate of ASD may continue to increase. So what are the Lurie Center for Autism and Mass General doing about this situation?

▶ We provide care for individuals with ASD across their lifespan, and in the last five years, we have had a 155% increase in the number of adults we care for.

▶ We have a physician that specializes in evaluating adults with developmental disabilities, and in training and educating physicians and other specialists — including optometrists, ophthalmologists and dentists — to develop expertise in working with adults with ASD.

▶ We have family resource specialists that have acquired expertise to support families in issues related to guardianship, living arrangements, job placements, and educational opportunities.

▶ We conduct workshops on transitions for parents where we provide information on how to begin to address each of these areas of need.

▶ The Autism Collaborative Care Project (highlighted in the story below) is set to make our entire hospital autism friendly, and create “best practices” that can be emulated across the country.

▶ We also have robust research and education efforts underway that you can read about in the following pages.

The Lurie Center for Autism is deeply committed to advancing care for individuals with autism over the lifetime, and also to furthering understanding of these complicated disorders. We hope you will consider joining with us to help to address these many pressing issues. With the $5 million challenge grant from the Nancy Lurie Marks Family Foundation, your investment will go further than ever.

Sincerely,

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

Mass General Addresses Accessibility for Individuals with Autism

“I have worried and avoided needed medical treatment for my son because it has always been extremely traumatic for him and our family. It’s not because it is so difficult for clinicians, but because there is a unique way to reach individuals with autism, that requires consistency, visual support, practice and patience....It is heartening to see that progress is happening at Mass General to help improve access to medical care.”

— Lurie Center Parent

Going to the hospital, or undergoing an operation, can be frightening for anyone. For a patient with autism, it is even more daunting. Mass General has cared for more than 8,000 people with autism over the past 10 years. When individuals with autism have medical issues, their communication, behavioral and sensory differences often make meeting their needs difficult in an office or hospital setting. While the Lurie Center is well equipped to address medical issues related to autism, it is equally vital that patients have access to appropriate, accessible and timely medical care to promote and maintain health and treat acute and chronic conditions.

In November 2013, with the support of the Ruderman Family Foundation and others, Mass General launched the Autism Collaborative Care Project to find ways to improve the hospital...

Continued on next page
Lurie Center Hosts World Premiere of “Sounding the Alarm”

On January 15, the Lurie Center, in partnership with Autism Speaks, hosted 150 guests at the premiere screening of “Sounding the Alarm,” a documentary that provides a poignant look inside the lives of those touched by ASDs.

Dr. McDougle spoke about current research that is shedding new light on these disorders. While highlighting some of the challenges faced by those with autism and their caregivers, the 60-minute film also had many bright spots. One father founded a car wash that is employing 34 individuals with autism and is an opportunity to empower these individuals and provide them with paying jobs. Bob and Suzanne Wright, co-founders of Autism Speaks, and their incredible efforts to make a difference not only for their grandson, Christian, but for everyone throughout the world affected by autism, were also featured.

"Our goal is to make the hospital experience the best it can be for patients with autism, and then share our successes with others so that hospitalized patients and their families feel supported and well cared for at a very vulnerable time. There is a great deal of energy and synergy in these groups to improve the process of caring for patients with autism.”

Peter Greenspan, MD
Vice Chair, Pediatrics
Co-Chair, Autism Collaborative Care Project

Accessibility (continued)

experience for patients with autism. This initiative builds upon the advocacy work of Lurie Center Leadership Council members Matt and Eve Megarel who became all too familiar with the hospital’s challenges in understanding and treating their now 24-year-old son Billy as he faced chronic health issues.

Working with Lurie Center providers, and Sarabeth Broder-Fingert, MD, then a fellow at MassGeneral Hospital for Children, the Megargels advised on the development of the Acute Care Plan for Autism (ACP). The ACP, which is a part of the patient’s electronic medical record, provides medical staff with a quick and easy way to learn about a patient’s sensory differences, communication methods and other potential stressors or safety concerns. Adults with an autism spectrum disorder or parents and caregivers are encouraged to complete the ACP survey. This can be found at www.luriecenter.org under the Support & Wellness tab.

The scope of the Autism Collaborative Care Project extends well beyond the ACP, and is ultimately aimed at building capacity across the hospital — both in inpatient and outpatient settings — to effectively address the healthcare needs of individuals with autism and other developmental disorders across their lifespan. A leadership committee — representing a diverse group of professionals in both the adult and pediatric domains of care — has been convened, and several working groups formed. One group will focus on autism awareness and provider education, so that staff have a working knowledge of autism and how the worlds of those affected work. Another group will look at communications to ensure that those individuals, who are often not able to articulate their symptoms or relate to others around them in traditional ways, have a means for expression. Still other groups will focus on hospital systems, developing recommendations for improving administrative processes such as scheduling, admissions, information transfer, and procedure preparation among other things. Safety and security issues are also being addressed.
Lurie Center for Autism by the Numbers

Patient Visits: 2009 vs. 2013
The Lurie Center has more than doubled the number of patient visits conducted annually.

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<tr>
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<th>2009</th>
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<td>Visits</td>
<td>2,482</td>
<td>6,570</td>
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<td></td>
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155% Since 2009
18% Since Last Year

2013 Lurie Center Patient Population: Children

1 in 68 children are affected by an Autism Spectrum Disorder

- 0-5 years: 21% of all patients, 17% of patient visits, 25% of new evaluations
- 6-12 years: 39% of all patients, 39% of patient visits, 36% of new evaluations
- 13-17 years: 18% of all patients, 19% of patient visits, 13% of new evaluations

Autism Spectrum Disorders are the fastest growing developmental disability, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. There is no known single cause for autism.

Early intervention services for preschoolers continue to grow, and nearly 500 children under the age of five were evaluated at the Lurie Center in 2013.
There are more adults living with autism than children, and an additional 500,000 children with autism will become adults during the next decade.

In 2013, adult patients accounted for:

- 22% of all patients
- 25% of patient visits
- 26% of new evaluations

The Lurie Center serves more than 500 adult patients, and in 2013 each patient visited the Center for care an average of three times.

The Lurie Center is one of the few autism centers in the United States to offer services over a lifetime. Lurie Center clinicians are preparing pediatric, medical and surgical colleagues across Mass General to care for individuals with autism in primary and specialty care practices, as well as in emergency room settings.

2013 Lurie Center Visits by Discipline

The Lurie Center’s multi-disciplinary approach promotes the best possible care for patients.

- 33% Neurology
- 27% Psychiatry
- 18% Gastroenterology
Lurie Center Clinical Revenue
The Lurie Center has diversified and expanded clinical revenue streams and has decreased reliance on funding from the Nancy Lurie Marks Family Foundation’s (NLMFF) founding gifts. Still, each patient visit requires at least a $133 philanthropic subsidy to provide a full complement of services.

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

Reimbursements for care, however, do not reflect the additional time medical providers invest in coordinating and delivering care to individuals with an ASD.

Gifts and grants from individuals and foundations help the Lurie Center invest in patient and family support services.
Lurie Center Research Revenue
This past year, the Lurie Center more than doubled its research revenue, growing from $1.1M in FY12 to $2.4M in FY13. This growth was primarily in philanthropy.

Lurie Center and Spaulding Rehabilitation Network
The Lurie Center partners with Spaulding Rehabilitation Network to offer therapeutic services to patients at One Maguire Road. These programs continue to grow in overall patient visits each year.

Increase in Visits
37% Since 2009
12% Since Last Year

2013 Spaulding Visits by Discipline
Speech visits comprise 51% of all Spaulding visits at the Lurie Center, and of those, 41% were for Alternative and Augmentative Communication services.
What’s New at 1 Maguire Road?

With January’s expansion at 1 Maguire Road, the Lurie Center more than doubled its size to 26,450 square feet. After months of construction, this change allows the Lurie Center to both expand and offer new services and events.

Importantly, the expansion has allowed the Aspire program to consolidate its headquarters to the Lurie Center and all program directors and administrative staff now work in a single location. Collaborations between Aspire and Lurie Center clinicians and researchers have already increased and the extension of services resulting from having both organizations based at one site benefits many patients.

The expansion also allows the Lurie Center to begin hosting on site educational programs for families. The Roger A. Bauman Parent Speaker Series is now being held at the Lurie Center in Lexington, as well as regular workshops for parents. As the final phases of the renovation and expansion are completed, the Lurie Center will begin offering even more activities and events for patients and families.

MGH Neurology is now offering outpatient electroencephalogram (EEG) services for patients. Providing this service in Lexington allows Lurie Center patients to complete EEGs in a familiar, calm environment. EEG services are available every Thursday for patients of all ages with a physician referral. The service is not limited to Lurie Center patients.

Yamini J. Howe, MD
Dr. Howe is a board certified development behavioral pediatrician. She joined the Lurie Center staff after completing a fellowship in Developmental Behavioral Pediatrics at Brown University/Rhode Island Hospital in 2013.

Dr. Howe has a strong interest in diagnosis and providing ongoing care for young children who have learning, behavioral or communication challenges, including ASDs. She works with families to coordinate and develop comprehensive treatment plans that may include medication and other therapies to support their child’s ongoing development.

Michelle Palumbo, MD
Dr. Palumbo is a pediatrician and a child and adolescent psychiatrist who joined the Lurie Center in August 2013, after completing a triple board residency program in Pediatrics/Psychiatry/Child and Adolescent Psychiatry at the Warren Alpert School of Medicine of Brown University.

Dr. Palumbo treats both the medical and psychiatric aspects of ASDs and other developmental disabilities. Dr. Palumbo works with the patients and their families to develop a comprehensive treatment plan that may include medications and other therapies in order to address each individual’s and family’s needs, as well as focusing on optimizing their strengths and abilities.

Lurie Center Clinic at 1 Maguire Road, Lexington

www.luriecenter.org
Research at the Lurie Center

Research is a core mission of the Lurie Center. Faculty members have forged partnerships with colleagues throughout the Mass General community and beyond to further the understanding and treatment of autism spectrum disorders.

The Lurie Center faculty bring a clinical perspective to the research process, helping scientists whose work is primarily based in the laboratory understand the many intricacies of ASD. Working together, these multidisciplinary research teams are engaged in studies that are shedding light on the neurological, psychological, physiological, social, and genetic components of autism.

**AUTOIMMUNE DISORDERS AND AUTISM**

One of Dr. McDougle’s research priorities is to explore the link between autism and autoimmune disorders. In his clinical practice, he noticed that a high percentage of his patients had family members with autoimmune disorders — such as rheumatoid arthritis, lupus or multiple sclerosis. These disorders develop when antibodies that normally fight infectious organisms attack the body itself. Individuals with autism also show signs of chronic immune system activation and inflammation that affect the brain. Many researchers think that this chronic inflammation starts before birth and may be triggered by a mother’s infection, allergies or autoimmune response.

The experience of having a grandson with autism led Bob and Donna Landreth of Midland, Texas, to connect with Mass General, where they met Dr. McDougle. In 2012, they pledged $5 million to support parallel preclinical and clinical studies to investigate maternal inflammation as a mechanism underlying a subtype of autism.

**BIOMARKERS AND GENETIC UNEPINSTALLINGS**

There is an unmet need for objective biomarkers to assist clinicians in the early diagnosis of neurodevelopmental disorders and the Lurie Center is collaborating on several investigations in this area. The center is one of 20 sites enrolling children in a SynapDx sponsored clinical trial to assess a novel blood test’s ability to accurately predict an autism diagnosis in children as young as 18 months old.

In another study, children aged 5-10 are being enrolled in a Boston Autism Consortium Study funded by the Simons Foundation to identify biomarkers associated with ASD. Through a relationship with Mass General’s Center for Human Genetics Research,
this study will also contribute to a rich biorepository to enhance genetic studies in autism and related neurodevelopmental disorders. Understanding the fundamental disease mechanisms underlying autism and identifying genes can lead to improved diagnostic capacity, better disease management and the development of rational treatments.

**TREATMENTS**

The Lurie Center continues to advance understanding of the most effective treatments for ASD through active participation in the National Institutes of Health (NIH) sponsored Research Units on Pediatric Psychopharmacology Autism Network and the Autism Speaks-Autism Treatment Network. The center is also a site for two exciting new federally-sponsored clinical trials.

The Autism Centers of Excellence award from the NIH is a multi-site project that will investigate the neuro-hormone oxytocin, given intranasally, for social and communication impairment in children and adolescents with autism. A naturally occurring hormone, oxytocin plays a critical role in sociability and affiliation. The study will measure improvements in social skills and communication and will use blood samples to conduct gene-based tests. The other is the Fast-Fail Trials in Autism Spectrum Disorders (FAST-AS) through a new National Institutes of Mental Health initiative. The overall goal of the FAST-AS initiative is to implement experimental medicine trials in adults — and then children and adolescents — with autism in order to quickly test and analyze whether medication holds promise.

This important research cannot occur without the participation of patients, families and individuals within the community.

If you are interested in receiving regular updates about autism-related research at the Lurie Center you can enroll in our Research Registry online via [http://j.mp/LatWGi](http://j.mp/LatWGi) or call our research office at 781.860.1711.

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**The Parent Mentor Program**

**An Initiative of Lurie Links**

No one understands the unique challenges of raising a child with an ASD better than parents and caregivers.

Join Lurie Links Parent Mentor Program to connect with other parents or caregivers along the journey.

**Give and get support by:**

- sharing experience and wisdom
- asking and listening
- problem solving together

**To learn more or to register, please visit:** [www.LurieCenter.org](http://www.LurieCenter.org) or contact the Family Support Team at 781.860.1730 or LurieCenter@partners.org

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The Lurie Center for Autism is committed to identifying the causes of a meaningful subtype of ASD and an accompanying treatment that will benefit those with ASD during their lifetime.
Aspire in the Workplace

In 2012, the renowned Aspire Program — formerly known as YouthCare — joined the Lurie Center. Aspire’s focus is on providing children, teens, and young adults with high functioning autism and related disorders with the knowledge and skills necessary to make social connections and develop independence leading to successful and fulfilling lives.

While the Aspire Summer Camp program has been serving children for more than three decades, families were increasingly looking for additional resources that could assist their children as they matriculated into the adult world. Last year, Aspire launched an Internship Program to help young adults on the spectrum navigate various aspects of a work environment, while gaining important on-the-job skills. Participants—generally those with high functioning autism, Asperger’s disorder or a related challenge—are often skilled in various aspects of a job or task, but have difficulty navigating the social world and understanding the office culture.

Through the program, interns are placed with employers, including Liberty Mutual, Mass General, Harvard Museum of Natural History, Safelite AutoGlass, and Copart where they work three days per week during their eight or 14-week internship. They also spend one day per week with Aspire, where they participate in group learning sessions focused on the hard and soft skills needed to succeed in the workplace.

“I know he’s learned a lot during his time with us, and we’ve learned quite a bit from him.”

Aspire staff provide training and ongoing support for those who supervise interns, which helps the employer utilize the individual strengths of each intern and be supportive of challenges that may arise at times. Aspire job coaches also meet with the interns and their supervisors regularly.

The goal of the Aspire Internship Program is to develop a model for replication in other parts of the country.

“He brings great organizational skills, attention to detail and terrific stamina and enthusiasm to the job every day.”

Melanie Foley
Vice President for Human Resources
Liberty Mutual

An intern in accounting at Liberty Mutual said, “My personal goal is to have a positive work experience for myself while contributing to the company and the people I work with, and successfully sharing my skills to benefit the team. I thank Aspire so much for giving me this opportunity.”

The Aspire Internship Program is made possible through the generosity of the many individuals and corporations who support the Aspire Gala, which is held annually in April. To learn more about Aspire, please visit: www.mghaspire.org.
For the past six years, Friends of the Lurie Center (FOL) volunteer Tracey Turgeon has been the force behind the FOL Marathon Team’s success. Since its inception in 2003, the FOL Marathon Team has raised more than $250,000 to support the family resource team at the Lurie Center, and its predecessor LADDERS. Tracey succeeded longtime FOL volunteer and runner Amy Weinstock as team coordinator in 2009. Grateful for the care that their younger son, Alec, now 9, was receiving at the Lurie Center, her husband, Marc, signed up to be a member of the 2007 FOL Marathon Team. His success inspired Tracey’s commitment.

As the team coordinator, Tracey’s role is to provide support and guidance to all runners throughout their training, including managing the logistics associated with race day. “Our runners have made it just a pleasure, as we share a common bond. We all have seen the strides that those with autism have made because of the phenomenal people at the Lurie Center,” she said.

Her work begins early in the year when a special friend of the Lurie Center donates bib numbers. “Our goal is to assemble a team that shares our passion for the work of the center, and will maximize the opportunity to raise funds,” said Tracey. “We’ve been fortunate to have Joey’s Team — this year comprised of brothers Mike, E.J. and Rob Freni, and friend Kevin Smith — who ran their seventh consecutive Boston Marathon. They have raised nearly $100,000 for FOL in honor of Mike’s son Joey, who receives care at the Lurie Center.”

Recognizing that the Boston Marathon is an enormous undertaking — both in training and fundraising — this year Tracey sought alternative opportunities for FOL. She secured 25 numbers for the Falmouth Road Race and is now actively recruiting team members to participate in this scenic, ocean side, 7-mile run.

The race will be Sunday, August 17, 2014, and the individual fundraising requirement is $750.* Tracey’s husband, Marc, was the first to sign up for this race. “My knees no longer allow me to train for marathons, so I am very excited for the opportunity to run again for FOL. I have participated in the Falmouth Road Race in the past, but this year will be even more meaningful because I will be fundraising for FOL.”

To join the team or learn more please contact Tracey Turgeon at (617) 755-1721 or fol@partners.org.

*There is an extraordinary fundraising opportunity this year. For every $1 donated to the Lurie Center in 2014, the Nancy Lurie Marks Family Foundation will generously donate an additional $2.
Educating and Supporting Parents and Care Givers

The Lurie Center continues its commitment to supporting parents, families, and caregivers through a variety of educational and family events. The quarterly Roger A. Bauman Parent Speaker Series continues to be well subscribed. In 2013, the center launched a more intimate series of workshops for parents/guardians of newly diagnosed patients, and those patients in the transition years. Workshops also included topics related to augmentative communication and sensory integration therapies.

With the support of the Ferrara family, Lurie Center clinicians developed a new support and wellness section on the website www.luriecenter.org that addresses common questions and concerns about ASDs with evidence-based answers. A series of social stories that can be used to prepare a patient for a visit to the center was also created.

In April, the Lurie Center hosted its 2nd annual “Meet the Experts Roundtable Forum” as a part of its Autism Awareness Month celebration. This evening of networking and learning is co-sponsored by the Friends of the Lurie Center.

To learn more about upcoming events, please sign up for our email list at FOL@partners.org
Preparing Clinicians to Care for Individuals with ASDs

A founding mission of the Lurie Center is to train the next generation of clinicians and researchers in the field of autism spectrum disorders (ASDs). With the expansion of the center, 32 MGH residents rotated through the clinic as a part of their training. The Lurie Center has also been a coveted placement for post-doctoral students who are interested in ASDs sub-specialty training. Through a new summer internship program for undergraduate students, the center welcomed five highly motivated students who are considering a future in the field of ASD care and research.

While a significant number of trainees at the Lurie Center continue to focus on ASDs throughout their career, those trainees who pursue other specialties will bring with them a solid understanding of the complexities of ASDs to their medical and research practices.

Faculty are also focused on ensuring that individuals with ASDs have access to primary and specialty care close to home, and have developed a series of trainings for community providers on best practices regarding the medical care and needs of their patients with ASDs. Efforts include developing and implementing a curriculum that is delivered onsite to community physicians, nurse practitioners and physician assistants.

Are you interested in helping those affected by autism and related developmental disorders?

JOIN FRIENDS OF THE LURIE CENTER!

Friends of the Lurie Center (FOL) is a growing group of volunteers dedicated to supporting the Lurie Center’s mission of providing quality services for individuals across the lifespan. FOL members help in both big and small ways through participation in educational programs, community outreach and fundraising events.

To learn more, email us at FOL@partners.org

Stay Connected

The Lurie Links newsletter will be printed and mailed to the Lurie Center community once annually. A supplemental e-newsletter will launch in the fall.

To sign up to receive the newsletter as well as invitations for upcoming events, please visit: giving.massgeneral.org/LurieEmail.

www.luriecenter.org
Meet the McFarlands

As a family, they are facing the challenges of an autism spectrum disorder.

They rely on the Lurie Center for Autism. The Lurie Center is working to ensure that young people, like Colleen, living with an autism spectrum disorder, have the brightest future possible. With the help of the Lurie Center’s programs and support, Colleen is learning to become more independent.

Invest in Colleen’s future and the futures of other patients by giving to autism research and patient care at the Lurie Center.

For every $1 you donate to the Lurie Center, the Nancy Lurie Marks Family Foundation will donate an additional $2.

To make a gift or to learn more contact Anne MacLean at acmaclean@partners.org or 617.643.0463.

You may also give online at: secure.massgeneral.org/lurie-center.