Jonathan’s Transition
One parent describes the unanticipated challenges her son’s entry into puberty posed for the family

By Amy Kratchman

By the time Jonathan was 10 months old, I was growing concerned. He was showing no interest in his peers and did not speak. When Jonathan was finally diagnosed with autism at age three, I finally had an answer to why he was not developing typically.

I read anything I could about autism, took him to every therapy I heard about within reason and met other families whose children were receiving early intervention. The doctors told us that he would need much assistance while he was young. Although I ran Jonathan from treatment to treatment, I always had a care plan.

I met other families, learned about their “journeys,” and gradually developed my own “handbook” to help guide our life with Jonathan.

My husband and I settled into our new life, considered “normal” for the world of autism. We embraced it and focused on Jonathan’s strengths and his innocence. When he was younger, he had a tendency just to cry and get upset when he thought he had done something wrong. However, this predictable behavior came to a crashing halt when puberty began.

(Continued on page 4)

TRANSITION AND THE CHILD WITH ASD: As more children are diagnosed with an autism spectrum disorder, more parents face the difficult and often unexpected behavioral changes that accompany adolescence. This issue highlights the concerns and confusion many parents feel, what they may expect, and how to plan for this period.

See page 3
The Autism Intervention Network on Physical Health (AIR-P) has made major strides in the past several months. Currently, the ATN sites provide services to around 27,000 children in the United States and Canada who have an autism spectrum disorder (ASD). Our goal is that all children with ASD will have access to quality, comprehensive, and family-centered care. We strive to meet this goal through the development and implementation of best clinical practices across the ATN sites, clinical guidelines, research into better treatments, and the patient registry, which collects information about our patients.

Over the past few years, the AIR-P has developed several clinical guidelines to help inform physicians and families about the best evidence-based care in key areas of diagnosis and treatment. These cover the treatment of constipation and insomnia, and medication choice for some behavior problems among children with ASD. The guidelines were developed through research and discussion about the best current practices, and we tested them in our centers.

We have also begun assessing the quality of care across network sites on an ongoing basis. We are using state-of-the-art methods to improve care at each site and across the entire network. We realize that parents are often the best judges of how we are doing. So parents have key roles on the improvement teams at each network site and are members of the new AIR-P/ATN Family Advisory Committee.

The AIR-P funding provided by the federal government allowed the network to expand research programs substantially. We now have 10 active research projects, and over 1100 children and adolescents with ASD have participated in our research studies. Five new projects have been approved for funding this year. All of our projects seek to answer the questions that parents bring about their children’s health care. Finding the right answers may take time. But we’re proud of the projects, which address such diverse issues as toilet training, nutrition, sleep problems and other concerns.

Initial funding from the Combating Autism Act for the AIR-P ended on September 30, 2011. The network successfully competed for funding for another three years to continue and expand this work with several new research projects (see related article on page 2), with expanded quality improvement efforts, and dissemination. New studies address weight gain in children taking risperidone and examine whether iron supplementation can improve sleep patterns in iron-deficient children with ASD and low iron levels. Three new projects, recently approved, address improving the emergency department experience of children with ASD and their families, stress and gastrointestinal disorders in children with ASD, and diagnosis of functional GI disorders in ASD.

The network registry now includes over 4,000 children and adolescents with ASD, making it one of the largest databases concerning ASD in

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About the ATN

The Autism Speaks Autism Treatment Network (ATN) includes 17 academic medical centers across the United States and Canada. A funded program of Autism Speaks, its mission is to expand access to comprehensive, multidisciplinary, quality medical care for children and adolescents with ASD within their local communities. ATN sites provide a full clinical program of diagnosis, assessment, and medical treatment for children and adolescents with ASD. The ATN supports a patient registry that tracks treatment and outcome information to support ATN clinical and research efforts. ATN clinicians also engage in research into associated medical conditions and their treatments.
younger populations. Under the guidance of Dan Coury, M.D., a number of physicians and researchers have used the registry to understand the relationships between children’s health and their behavior and functioning. In the past two years, the ATN has received and reviewed more than 50 separate requests for analysis of registry data. Here again, the goal is to gain knowledge that can guide new treatments and help children make the most of their behavioral and educational programs.

Already, network data have supported numerous research studies and have been presented at the International Meeting for Autism Research (IMFAR), meetings of the Pediatric Academic Societies, Associated Professional Sleep Societies, and other national and international conferences. As the registry expands to include more information from the ongoing visits of children in the network, we will be able to add further scientific insights into what treatments and characteristics affect a child’s functioning and well-being over time.

The Combating Autism Act has had major benefits in many areas of autism identification, diagnosis, and treatment. The Act has supported not only our activities but also activities at the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH) and HRSA. HRSA supports not only the AIR-P, but also major training programs and other research to strengthen knowledge about ASDs. It also supports the workforce of healthcare providers for ASDs. Renewal of the Act was critical to maintain and expand these very important efforts for families.

**About the AIR-P**
The Autism Intervention Research Network on Physical Health (AIR-P) consists of 14 ATN sites working together to improve the physical health and well-being of children and adolescents with autism spectrum disorders and other developmental disabilities. AIR-P funding supports efforts in five key areas: research on evidence-based healthcare practices; training and mentoring of new researchers and clinicians; developing medical practice guidelines and tools; circulating critical healthcare information to professionals and families; and transferring new knowledge into medical practice for improved care.
Promising Research

New AIR-P Studies Funded

Funding made available by the Health Resources and Services Administration (HRSA) in September 2011 for the Autism Treatment Network’s AIR-P activities (see related story on inside cover) will support two new major research studies. One will look at the use of Metformin (a drug often used in diabetes to help control blood sugar) to reduce weight gain in children with autism taking atypical antipsychotics. The other study will examine the use of iron, taken in small amounts, to treat sleep disorders in children with autism who have low iron levels.

Treatment of Overweight Induced by Antipsychotic Medication in Young People with ASD

Atypical antipsychotics (such as Risperidone and Aripiprazole) are the only medicines in the U.S. specifically approved for use in children with autism to improve problem behaviors such as agitation and irritability. These medications often cause troubling increases in body weight. Although weight gain may be reversible if the medications are discontinued, simply stopping these medicines is rarely an option. The researchers would like to learn if Metformin may lessen weight gain in children who require atypical antipsychotics.

The researchers plan to recruit 90 participants between the ages of 6 and 17 who have been prescribed an atypical antipsychotic. One group will receive Metformin, and the other will receive a placebo (sugar pill). By studying the two groups, the team will try to determine if Metformin is safe and effective for reducing weight gain in children taking atypical antipsychotics.

Evdokia Anagnostou, M.D., a scientist at Bloorview Research Institute is leading the three-year study. The team also includes investigators from University of Pittsburgh Medical Center (Benjamin Handen, Ph.D.), Vanderbilt University Medical Center (Jeremy Veenstra-Vanderweele, M.D.), and Ohio State University (Mike Aman, Ph.D.).

Iron Treatment of Sleep Disorders in Children with Autism Spectrum Disorders

Insomnia is common in children with autism. This difficulty in sleeping can hamper a child’s development and behavior and the family’s quality of life. Children with autism may suffer from insomnia for a variety of causes including environmental, behavioral, and medical reasons. The body needs small amounts of iron for building cells and delivering oxygen to muscles and tissues. The researchers are interested in iron’s role in improving sleep in children with ASD and whether iron treatment can also affect Restless Legs Syndrome (RLS) and Periodic Limb Movement of Sleep (PLMS), limb movements that are often associated with sleep difficulties.

The researchers plan a 3-year, 2-phase study to evaluate whether taking an oral iron supplement reduces sleep problems. They plan to recruit 180 children between 3 and 10 years of age who have trouble sleeping and have low iron levels. The study will split the children into two groups. One will receive the iron supplement; the other will receive a placebo (sugar pill). Families will monitor their child’s sleep using a sleep diary. The child will wear an actigraph (a small device, worn like a watch, to measure movement during sleep). The team will study whether the iron is useful in improving sleep in children with autism and in reducing limb movements.

Ann Reynolds, M.D., a clinician and scientist at Children’s Hospital Colorado, is leading the three-year study. The team also includes investigators from the University of Rochester Medical Center (Heidi Connolly, M.D.), Holland Bloorview Kids Rehabilitation Hospital (Shelly Weiss, M.D.), and Vanderbilt University Medical Center (Beth Malow, M.D.).

For more information about AIR-P research activities, please visit: http://www.autismspeaks.org/airp
Enhancing Patient Care through Quality Improvement

From the start the ATN/AIR-P has been devoted to improving the quality and availability of medical care for children and adolescents with ASD. We have been developing uniform approaches for diagnosing and treating ASD and associated conditions. We have collected a wealth of information to describe patient progress—and our own. And we have researched an array of topics that are particularly important to people with autism and their families.

Recently we have increased our focus on ensuring that ATN centers provide the best possible care for their patients and families. So we are excited to have begun a new quality improvement initiative, the “Collaborative to Improve Care for Children with Autism Spectrum Disorder.” ATN site teams, including parent and community partners, have begun working together to make vital changes to help the network deliver higher quality care to children with ASD. Led by the National Initiative for Children’s Healthcare Quality (NICHQ), the Collaborative uses an approach known as the Breakthrough Series Model, which has helped other healthcare providers improve their processes and practices.

NICHQ and the ATN/AIR-P agreed on goals and priorities in March of last year, working with parents and experts in both quality improvement and healthcare for children with ASD. Last June, ATN centers selected their team members and met to develop plans for making changes at their sites. Teams are now testing small changes, tracking progress, and sharing successes and challenges online and through monthly conference calls.

Although still early in the collaborative process, sites have already instituted changes that will benefit children and families.

Transition and the Child with ASD

As the ASD population increases, more and more parents are facing the difficult and often unexpected behavioral changes that accompany adolescence. The articles that follow, written by parents and physicians, highlight the concerns and confusion many parents feel, what they may expect, and how to plan for this period. We offer hope and encouragement with the message that the transition to the teenage years does not necessarily have to be turbulent and that families can find good ways to enhance the development of their child with ASD at this time.

Autism Speaks has recognized that children with ASD are aging into their teen years and adulthood with few resources to help them and their families make this great transition, and has been developing resources to help families plan for this period.

Autism Speaks’ Transition Tool Kit was created to guide families on the journey from adolescence to adulthood. It helps parents plan and locate useful resources and services that will make this transition more effective and successful.

Resources:
The Transition Tool Kit can be downloaded or ordered in hard copy here: http://www.autismspeaks.org/community/family_services/transition.php.

In addition, new tool kits to help parents decide whether to use medication to control their child’s behavior and physicians and parents to manage blood draws more effectively can be downloaded here: http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use

Other on-line resources
Locate resources by zip code: http://www.autismspeaks.org/community/fsdb/search.php

Services for adults with autism: Advancing Futures for Adults with Autism http://www.afaa-us.org
I remember other parents saying that adolescence was a tumultuous time for families. But I didn’t realize how little I knew about this time of transition for Jonathan. I no longer had that handbook; our clear plan for care and support did not seem to exist anymore. It felt like we had been given the diagnosis all over again. Gone were the days of Jonathan getting upset and crying or stomping his feet. Now when he got upset, he would go into a full-blown, aggressive tantrum. He seemed to lose all self-control, and the emotion would just take over.

I had always thought of myself as an advocate for my child, savvy about the latest treatments. But as Jonathan entered puberty, I missed some early warning signs. For example, what started out as biting small holes in his shirts in anxiety had turned into biting big holes during outbursts of anger. We began seeing a new Jonathan, one who experienced waves of anger. And we never knew what would set him off. We needed new guidance and a new handbook.

Families need more information on this important phase of their children’s lives. They need something more than “autism and puberty can be a volatile mix.” We heard that time and time again. What we did not hear was what to do about it.

We didn’t understand that, because Jonathan had entered puberty, medications that had once worked were now being metabolized by his body more quickly. We didn’t know what lay ahead and worried whether he would be able to control his outbursts and anxiety.

The doctors told us that Jonathan had a mood regulation disorder along with the autism. We found ourselves discussing new mood-controlling medications with frightening names. Suddenly my family was sliding into a grieving process similar to the one we experienced when our son was first diagnosed. We looked for information on the transition process, but found little; most of the focus in autism at that time was on early intervention.

We felt so alone.

Eventually, Jonathan, who is now 14, stabilized—with the help of two medications and behavioral therapy. He is learning how to cope when he begins to feel out of control.

Recently, I spoke with the mother of one of his friends. She hesitantly told me that her son was in a short-term facility to get his medications changed, because he had spiraled out of control. He is also going through puberty. She expressed the same loneliness and grief I once felt. I hear other parents say similar things.

There is a great need for more information about this transition phase for children with autism. Doctors can assist by preparing parents early, even before the onset of puberty. Puberty is hard enough for a typically developing child, let alone for a child with a disability.

With its new Transition Toolkit, Autism Speaks has begun the important dialogue with families struggling through this time. As intense as our focus should be on the causes and treatment of autism, I am happy to see attention shifting to this critical transition period in the lives of children with autism and their families.

Amy Kratchman is the mother of three children (a 14-year-old son with autism and both a 10-year-old son and a 6-year-old daughter with mitochondrial disease). She is active in the developmental disabilities community and a family consultant for the Children’s Hospital of Philadelphia (CHOP), where she serves as the director of their LEND (Leadership Education in Neurodevelopmental Disabilities) family collaboration program. She is also a member of CHOP’s Family Advisory Council and offers the family perspective to numerous hospital and community committees and project groups.
Developmental Milestones in the Child with ASD

As children grow and mature, we can predict certain milestones – first steps, first day of school, first tooth to fall out and so on. Children with ASD are no different in most respects. But they may deal with these experiences differently from other children. For example, toilet training in typically developing children occurs between ages 24 and 60 months. This is when most children gain control of body functions and greater awareness of social expectations. Many children with ASD face obstacles that delay acquiring such skills. These challenges can include sensory problems that hamper awareness of physical sensations, thinking difficulties that limit understanding of expectations, and a lack of social awareness of expectations and norms. Though ASD can complicate the development of such skills, most affected children can master them with informed assistance. For parents, awareness of these milestones and the challenges some may pose for a child with an ASD can help prepare them to assist their child appropriately. Here is a list of some of the common milestones in typically developing children that parents can anticipate in their children with ASD.

Daniel Coury, M.D.
ATN Medical Director
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<thead>
<tr>
<th>Age Range</th>
<th>Milestones/Potential Challenges</th>
<th>Medical Concerns</th>
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<tbody>
<tr>
<td>Toddler – to – Preschool</td>
<td>Challenges with toilet training; self-feeding skills; communication</td>
<td>Challenges with toileting may lead to constipation, sleep issues</td>
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<tr>
<td>Preschool – to – School</td>
<td>Increasing self-directed activity under supervision of other adults; increased social interactions with peers; cooperative play becoming common</td>
<td>Signs of inattentiveness, over-activity, impaired coordination may first become evident. Medications may be considered, but structured environment often adequate.</td>
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<td>School age</td>
<td>Larger class sizes; riding buses; increased exposure to larger groups of peers; longer periods away from home (6 hour school day); increased involvement of other adults; youth sports activities</td>
<td>Increased expectations of on-task behavior and productivity may make inattention and sleep issues more prominent. Medication may be considered if not already started</td>
</tr>
<tr>
<td>Middle school</td>
<td>Pre-adolescent social changes; school sports activities as social events</td>
<td>Pre-puberty changes - growth spurt, difficulty falling asleep</td>
</tr>
<tr>
<td>High school</td>
<td>Adolescent changes in body and brain and their effects on behavior</td>
<td>Pubertal changes – voice, body hair, secondary sex characteristics – may cause anxiety or upset. Normal brain developmental changes can lead to increased impulsivity, increasing emotional displays. Discuss with your child’s doctor any changes in behavior that might indicate a medical problem.</td>
</tr>
<tr>
<td>Post-high school</td>
<td>Transition to post-school education; employment; housing decisions; adult medical care; guardianship</td>
<td>Continue to promote healthy life style in diet, exercise, personal hygiene.</td>
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Are Turbulent Teen Years Unavoidable?
Not necessarily!

By Susan L. Connors M.D.
Julie O’Brien, M.Ed., LMHC

Puberty can be an unsettling, unpredictable and chaotic experience for children with an autism spectrum disorder (ASD) and their parents. This time can evoke feelings of uncertainty, unpreparedness, and fear even in the most loving, competent parents. Just when you were feeling comfortable, perhaps even confident, with your child’s education and treatment, you face an entirely new set of challenges. New behaviors may surface, including emotional outbursts, self-injury, property destruction and displays of anxiety that can challenge even the most stable family.

Typically developing children often meet puberty and its hormonal surges with upheavals in emotional regulation, changes in relationships with parents, and increased social and bodily awareness. In children with ASD, the same forces are at work. But these children have fewer natural coping mechanisms with which to handle new physiologic swings and interpersonal dynamics. Several sources of information and support are available to help you prepare for this transition.

COMMUNICATION
An important concern is communication, an especially acute need for adolescents who are nonverbal or near so. At the MGH Lurie Center, we see many adolescents and young adults whose behaviors improve once they are able to communicate their needs, desires and feelings. Importantly, we have clinically tested methods for helping adolescents understand and prepare for new experiences. These include Augmentative and Alternative Communication (AAC) evaluations and recommendations for aids such as picture schedules and electronic devices (with or without speech output). The technology behind such aids is becoming more accessible, affordable and creative.

Educators familiar with ASD often recognize puberty as another “window of opportunity” for social learning. Many children with ASD develop enhanced social awareness and greater interest in communication during puberty. Again, it is important for a child to have workable, age-appropriate methods for communication, as well as opportunities to learn, practice, and utilize appropriate social skills.

Many adolescents who lack functional language are helped by a form of psychotherapy called Cognitive-Behavioral Therapy, which can be used to teach relaxation and coping strategies, particularly in the face of anxiety.

BEHAVIORAL ISSUES
As mentioned, hormonal changes can increase frustration and aggression in the teen years. This, in turn, can lead to new rituals and obsessions during unstructured time such as after school, weekends and during community outings. Naturally, behaviors that are tolerated at home in a younger child may not be acceptable from a teenager in public. As a result, we see an increased need for intensive, consistent behavioral programs during these years. The goal is to help generalize skills, or extend them from the counselor’s office to the real world.

Another resource to consider is a psychopharmacological assessment by someone with expertise in ASD and co-occurring disorders. This can be particularly helpful for the teen experiencing mood changes, anxiety, related aggression, property destruction or self-injury (if there is no identified reason for these behaviors). Often, the closely
monitored use of behavior-modifying drugs can enhance your teen’s quality of life. This type of treatment may be a temporary measure that can be weaned or discontinued in the post-pubertal years.

SLEEP
Disrupted sleep patterns are another common problem during puberty. Sometimes this stems from anxiety related to increased social awareness. And like typically developing teens, those with ASD have a tendency to stay awake until progressively later hours. By lowering the length and quality of their sleep, this can further reduce your teen’s tolerance level and ability to cope. Here again, intensive home behavioral programs can help. Puberty is also a time to concentrate on life skills for independent living, such as hygiene, dressing and safety awareness. This can be done through home and school programs and should include education about sexuality (including such topics as “good touch/bad touch”). Trainings and conferences may be helpful, and there are many books and other resources on the subject.

THE IMPORTANCE OF PLANNING
Along with these concerns consider vocational planning as your teen progresses through puberty. What are his/her interests and strengths? How can these preferences be channeled into a sustainable vocation? What services are available for vocational assessments? Some state education departments start this process as early as age 14. Transition services and activities should include a vision and plan for post-secondary and vocational education, employment, independent living and community participation.

LOOKING FOR UNDERLYING CAUSES
In addition to managing any hormonal, behavioral and communication challenges, this is a time to start thinking creatively about long term and legal and financial planning for the child with ASD. Will you obtain guardianship? If so, will it be full or limited guardianship? What is your plan for your child’s health, safety and quality of life after you are gone?

Our closing thought involves good detective work. At the Lurie Center, when presented with new problematic behaviors in teens with ASD, we first look for an underlying medical cause. For example, the 12-year-old who returns to mouthing objects or head banging may have molars erupting, a toothache, or an underlying GI problem or sinus infection. Pain, as well as frustration, can lead to aggression and self-injury. We see an increasing number of individuals with ASD who have esophageal reflux and constipation, whose behavior improves with treatment. Having such possibilities in the back of one’s mind—and investigating them—can help the family avoid long, frustrating emergency room visits and help contain health care costs in the long term.

Fortunately, resources are available to help families cope. Teen years do not have to be as unsettling or impossible as parents may anticipate.
This year, as our son Luke’s 11th birthday approached, my husband and I planned his party with him. We had anticipated that he would want a Transformer themed birthday party, so it was quite a surprise when Luke announced that he wanted to have an Autism Awareness Party. “You know how some people think that Autism is a disability,” he said. “Well I actually think it’s a gift!” What a proud moment for us.

Luke told us his thoughts. He wanted to teach everyone about autism and provide them with real-life experiences. He suggested that we use puzzle pieces as decorations and have the guests wear red, yellow, light blue, or royal blue. We incorporated his ideas, placing a decorated tree in our dining room. We had puzzle piece cookies, which his Aunt Sue baked, and brightly colored cupcakes.

Luke, with his autism teacher, Mr. Stupnik and his autism coach, Mrs. Quintana made sure that we put blue light bulbs in the lamps around the house in recognition of the “Light it Up Blue” campaign. We hung posters that incorporated his autism classroom’s motto. They read, “I am not looking for a cure, I am looking for acceptance!”

By Rae Deane Gebbink
On the day of the party Luke greeted the guests, handing out wristbands that read, “I LOVE SOMEONE WITH AUTISM.” Surrounded by his family, friends and teachers, he opened his presents. All the gifts were special, but one of his favorites was the Autism Awareness ‘Scentsy’ burner. Then Luke presented the information that he had put together about autism. Although he was nervous, we could see he felt proud; it just radiated from him! The guests were just as proud. There was not a dry eye in the room.

It was a moving and inspirational day for all of us. Our family had worked together to help Luke achieve and celebrate his vision. Although my husband and I had initially struggled with whether we should teach Luke about autism, this party affirmed that doing so— and celebrating his strengths—were exactly the right things to do.

The following month, Luke participated in the Walk Now for Autism in Denver and raised $535.00 for Team Luke.

The Gebbinks: Libby, Shane, Luke, and Rae Deane