

**The Children's Hospital of Philadelphia Neonatal Follow-Up Program**  
**Narrative of Activities since January 1, 2011**  
**Presented to: The Oscar G. and Elsa S. Mayer Family Foundation**

From January 1, 2011 through June 30, 2011, forty-nine MCHAT screenings were conducted by our program. Four children were diagnosed with an autism spectrum disorder by our program: two older children (outside of the age range for the MCHAT) were diagnosed with autistic disorder; and two children referred from other Penn/CHOP affiliated follow-up programs after failed MCHATs were diagnosed with PDD. Five children failed the screening, and all five were deemed to have failed due to developmental delays rather than suspected autism. However, one child who passed the MCHAT had a clinical presentation concerning for autism and follow-up evaluation was offered but refused by the family.

Support from The Mayer Family Foundation also helped support our social worker, Ms. Calvert, with the ability to regularly follow-up with families at one and six months following diagnosis and later as needed to address important issues surrounding access to services. She has been able to assist several families with education by not only providing the resources that we have created, but also making them aware of other available resources such as a seminar for parents of children newly diagnosed with autism, hosted by the Center for Autism Research at CHOP. Ms. Calvert has played a pivotal role in helping improve families' access to services. When families first request services after receiving a diagnosis, they are at times met with resistance from early intervention providers about increasing services, or they encounter other roadblocks in navigating the system to identify appropriate services. Ms. Calvert has been able to assist families in overcoming these obstacles and help institute the appropriate therapies and services for their children.

Lastly, follow-up support for families of children with an autism spectrum diagnosis is essential, and our timing of support one month post-diagnosis is an especially critical time. As a case in point, a family of one child diagnosed during the current reporting period, had difficulty obtaining access to services despite diligently pursuing support through the recommended channels. Without ongoing support to navigate the process of receiving social security for their child, the family was at a roadblock for moving forward with recommended treatments. Checking back with this family at one-month post diagnosis allowed our team to provide critical ongoing support to help the child and family moving forward. It is essential to have support personnel who are trained in the specific obstacles that families of children with autism might face. With trained staff, we can most effectively help families and children navigate the complex medical, behavioral health, insurance and early intervention systems, in order to receive the most appropriate treatment and maximize children's outcomes.

We trust that the Foundation finds these updates encouraging as we are proud of our continued success with this program for children with autism and their families. Thank you for the ongoing support and we look forward to reporting more outcomes of the program later this year.

Judy Bernbaum, MD  
Director, Neonatal Follow-up Program  
The Children's Hospital of Philadelphia

**The Children's Hospital of Philadelphia Neonatal Follow-up Program  
Interim Grant Report to the Oscar G. and Elsa S. Mayer Family Foundation: July 2011**

With the initial funding from the Oscar G. and Elsa S. Mayer Family Foundation, the Neonatal Follow-up Program had three desired outcomes:

1. To provide a full diagnostic evaluation for autism spectrum disorder (ASD) soon after failure on autism screening;
2. To help families develop a thorough understanding of ASD and its impact on their child, as well as what treatment and support services are available;
3. To assist families to obtain services in a timely manner.

In the 2009 and 2010, additional goals were added:

4. Expand our follow-up assessment of ASD to include additional medical diagnostic screening when indicated;
5. Expand our educational resources offered to families. Particularly, providing books that would be helpful in their understanding of ASD and obtaining services and employing useful intervention techniques at home;
6. Expand our follow-up of patients diagnosed with ASD to include gathering information about longer-term outcomes;
7. Tailor the timing of autism screening to best meet the needs of our preterm infants who have developmental delays.

1. **Timely Full Diagnostic Evaluation:** Since January of 2009, the Neonatal Follow-up Program's psychologists, Marsha Gerdes, Ph.D., and Casey Hoffman, Ph.D., have been trained in the use of the *Autism Diagnostic Observation System* (ADOS), the gold standard tool for diagnosis of autism spectrum disorders (ASDs). This has proven to be the essential element to reducing the wait time between a failure on the *Modified Checklist for Autism in Toddlers* (MCHAT), a parent report screening tool that prompts a suspicion of autism, and a formal diagnosis. We are now able to offer diagnostic testing on a timeline that is most appropriate to the child's developmental level and is best suited to the needs of the family. From January 1, 2011 through June 30, 2011, 49 MCHAT screenings were conducted by our program. Four children were diagnosed with an autism spectrum disorder by our program: two older children (outside of the age range for the MCHAT) were diagnosed with autistic disorder; and two children referred from other Penn/CHOP affiliated follow up programs after failed MCHATs were diagnosed with PDD. Five children failed the screening, and all five were deemed to have failed due to developmental delays rather than suspected autism. However, one child who passed the MCHAT had a clinical presentation concerning for autism and follow-up evaluation was offered but refused by the family.
2. **Understanding of Autism and Accessing Support Services:** Funding has supported the creation of a comprehensive resource binder to provide families upon diagnosis of an ASD. The purpose of this binder is to help families navigate the vast array of information available about ASDs and to compile the most pertinent information needed after diagnosis. The resource binder is updated annually and reviewed with families at the time of diagnosis. Funding also provided our social worker, Ms. Calvert, with the ability to regularly follow-up with families at one and six months following diagnosis and later as needed to address important issues surrounding access to services. She has been able to assist several families with education by not only providing the resources that we have created, but also making them aware of other available resources such as a seminar for parents of children newly diagnosed with autism, hosted by the Center for Autism Research at CHOP. Ms. Calvert has played a pivotal role in helping improve families' access to services. When families first request services after receiving a diagnosis, they are at times met with resistance from early intervention providers about increasing services, or they encounter other roadblocks in navigating the system to identify appropriate services. Ms. Calvert has been able to assist families in overcoming these obstacles and help institute the appropriate therapies and services for their children.
3. **Expansion of follow-up assessment for ASD:** In order to provide a complete evaluation of children diagnosed with ASD, our assessment includes testing for other possible etiologies of ASD including, Routine chromosomal testing (karyotype), Fragile X molecular DNA probe, FISH probe for 22Q deletion and a metabolic screen (for children demonstrating a clear history of regression).

These tests were ordered directly for 75% of patients who were diagnosed with an autism spectrum disorder by our program during the current 6 month period. For the remaining 25%, the need for follow-up testing was communicating to the referring physician.

4. **Expansion of educational resources offered to families regarding ASD:** Funding from the Mayer Family Foundation has permitted us to provide families with the following resources:
  1. *Children with Autism: A Parent's Guide*, 2. *Initiations and Interactions: Early Intervention Techniques for Children with Autism Spectrum Disorders*, and 3. *Engaging Autism: Using the Floortime Approach to Help Children Relate, Communicate, and Think*
5. **Long-term follow-up of children diagnosed with ASD:** A goal from our last reporting period was to create a follow-up questionnaire for parents regarding their children's functioning after they graduate from our program at age five. Data would be used to better understand long-term outcomes for our population and more effectively counsel families. This questionnaire is currently in the final stages of development as our first cohort of children is beginning to graduate.
6. **Collaboration:** Funding from the Mayer Family Foundation grant has allowed for increased collaboration between community pediatricians and area neonatal follow-up programs that refer their patients to our program for a comprehensive evaluation and diagnosis. We have also evaluated children referred to our Regional Autism Center who have high-risk neonatal histories in order to provide these patients with faster access to evaluation, diagnosis and initiation of services. This expanded medical protocol also provides a context for collaboration between our physicians and children's primary care doctors. Our social worker has participated in a bi-monthly meeting of autism specialists in the Philadelphia area to discuss relevant policy, resources, and challenges. This process has proved essential for developing consensus of best practices for helping children with autism and their families.
7. **Additional Accomplishments:** Dr. Gerdes has participated in a new autism integration planning committee at CHOP which aims to streamline access to autism evaluation and treatment for families while promoting communication and resource sharing between multidisciplinary providers. An additional goal is to ensure that each child receives a standardized evaluation consistent with best practices for identifying autism spectrum disorders.
8. **Unanticipated Challenges:** In addition to ongoing insurance challenges discussed in previous reports, an unanticipated challenge in the current six month period was our social worker's transition to a new position outside of our Program. For the past three months we have continued to provide our families with post-diagnosis counseling and assistance with access to autism-specific services. However, we have discovered that having a social worker on staff that is familiar with this diagnosis is essential to providing the most benefit to our families. Our on-call social worker has assisted with these tasks when possible, but a social worker with experience in autism spectrum disorders is crucial to providing families with comprehensive and effective support in this area. A new social worker has been hired and will be starting the last week of July 2011.
9. **Next Steps and Priorities for the 2011 Year:** These are our ongoing priorities for the 2011 year:
  - **Individualized Screening:** We will go beyond the 24 month corrected age visit and re-administer the MCHAT at the 30 month visit when developmentally indicated (see second item in Lessons Learned section). In the current six month period this has been added to our assessment protocol.
  - **Long Term Follow-up:** A follow-up questionnaire for families of children that participated in the program in order to gain a better understanding of outcomes for children after they graduate from the Program has been in progress and will continue with the new social work support we will be receiving at the end of July.
  - **Advocacy:** We will continue to advocate for funding and insurance contracts that will provide coverage and allow access to our program to a greater number of potential NICU patients. This has been ongoing, and we have also reached out to the new business manager for the Department of Child and Adolescent Psychiatry and Behavioral Sciences for assistance with this mission.
  - **Broadening Outreach:** We would like to reach beyond our neighboring neonatal follow-up programs and the Regional Autism Center to ensure that all providers in the broader CHOP care network (40 sites) are aware that their patients with high-risk neonatal histories and suspected ASD can be evaluated within our Program.

10. **Lessons Learned:** Follow-up support for families of children with an autism spectrum diagnosis is essential, and our timing of support one month post-diagnosis is an especially critical time. For one child diagnosed during the current reporting period, the family had difficulty obtaining access to services despite diligently pursuing support through the recommended channels. Without ongoing support to navigate the process of receiving social security for their child, the family was at a roadblock for moving forward with recommended treatments. Checking back with this family at one-month post diagnosis allowed our team to provide critical ongoing support to help the child and family moving forward. It is essential to have support personnel who are trained in the specific obstacles that families of children with autism might face. With trained staff, we can most effectively help families and children navigate the complex medical, behavioral health, insurance and early intervention systems, in order to receive the most appropriate treatment and maximize children's outcomes.

We remain grateful for to the Oscar G. and Elsa S. Mayer Family Foundation's funding on behalf of our families and children facing autism spectrum disorders. Through this support, we have been able to improve our screening, evaluating, diagnosing and supporting families in accepting the diagnosis and overcoming obstacles for treatment.