

**The Children's Hospital of Philadelphia
Neonatal Follow-Up Program
Snapshot of Activities since March, 2010**

Since March, we have continued to reach out to all of the families in our program who have a child diagnosed with autism. All new families receive our autism resource binder (described below in the 2008 Final Report). One family in the program moved to Florida shortly after their diagnosis and a packet was put together for them with Florida resources. Families have begun attending programs – one child is attending preschool for children with autism, along with receiving water therapy and horseback riding.

Based on our completed and submitted development assessments, we have been able to secure additional support services for families through community early intervention programs and school systems. Sensory integration and behavioral therapy are not standard programs offered, but, with our recommendations, we have been successful in obtaining these necessary services. We have also assisted two families in getting private speech therapy and vision therapy, along with wrap-around services throughout the summer so that skills will not be lost while out of school.

Additionally, through our program support, two families have benefited from community financial programs that assist families with non-medical expenses due to change in income due to their child's diagnosis – for example, going from full-time to part-time work, one parent not returning to work due to multiple medical needs, appointments, therapies, etc.

We are proud of the continued progress and success of this program for children with autism and their families. Thank you for the ongoing support of the Mayer Family Foundation, 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 Neonatal Follow-up Program of The Children's Hospital of Philadelphia

Final Grant Report to the Oscar G. and Elsa S. Mayer Family Foundation

The Neonatal Follow-up Program, through generous funding from the Oscar G. and Elsa S. Mayer Family Foundation, had three specified desired outcomes from this grant:

1. Providing a full diagnostic evaluation for autism soon after failure on an autism screening;
2. Helping families develop a good understanding of autism and its impact on their child, as well as what treatment and support services are available;
3. Assisting families to obtain services in a timely manner.

The program has been quite successful in meeting these goals, as follows:

Full Diagnostic Evaluation: In January of 2009, the Neonatal Follow-up Program's psychologists, Marsha Gerdes, Ph.D., and Casey Hoffman, Ph.D., were trained in the use of the *Autism Diagnostic Observation System* (ADOS), the gold standard tool for diagnosis of autism spectrum disorders (ASDs). With the ability to perform this evaluation within the program, Drs. Gerdes and Hoffman have been able to conduct the evaluations as quickly as the same day or within a week. This reduces the stress of uncertainty on parents and allows them to begin arranging treatment for their children at an earlier age, which is known to be related to better long-term outcomes. Because the team can assess children without charge, there are no delays while families seek approval from insurance companies for continued evaluation and care.

Between January 1, 2009 and March 15, 2010, 126 children were screened using the MCHAT. Of the 21 who failed the screening, the Neonatal Follow-up Program conducted ADOS evaluations on the six children who were deemed appropriate for further evaluation, four of whom were diagnosed with ASD. In addition, one child was diagnosed with ASD after the failed MCHAT screener without the need for ADOS testing. This represents a 4% rate of ASD in children who were screened using the MCHAT, compared with the national average of 0.7% (a six-fold increase in prevalence).

Of the six children who failed the MCHAT and were deemed appropriate for further evaluation, two were tested the same day, one was tested within a week, one was tested within one month, one was tested in three months, and one was tested in five months. For the child who was tested in three months, it was decided that due to her significant developmental delays, delaying testing to allow for some developmental progression would yield more reliable findings on follow-up testing. For the child who was tested in five months, multiple appointments beginning within one month of the failed screener were scheduled and then cancelled by the family. Children referred from outside follow-up programs were scheduled within one month of referral.

Of the remaining 14 children who failed the MCHAT screening, 10 were false positives due to developmental delay, two were false positives due to parent misunderstanding of the items (revealed on further follow-up interviews), one was deemed to be a false

positive based on clinical judgment, and one family declined to return for follow-up assessment. Sixty-two percent of the children screened had been admitted to the Ronald and Harriet Lassin Newborn/Infant Intensive Care Unit (NICU) after birth. The other children were referred by physicians, other hospitals, or concerned parents.

Understanding of Autism – Its Impact and Support Services: The Mayer Family Foundation funding has allowed the Neonatal Follow-up Program’s social worker, Deborah Calvert, M.S.W., L.S.W., and psychologists, Casey Hoffman, Ph.D., and Marsha Gerdes, Ph.D., to create a comprehensive resource binder of information to provide to 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 by families after a diagnosis (a copy will be sent to the foundation). Ms. Calvert spends time reviewing the information in the binders with families to increase their knowledge about the resources available to them and answer any questions that they may have.

Providing Services in a Timely Manner: In addition to Drs. Gerdes and Hoffman providing follow-up ASD testing in a timely manner, Ms. Calvert has followed up with each family by phone periodically to help support families as they come to terms with an ASD diagnosis, and remove barriers to treatment for their children. This follow up can take many forms, from assisting with registering children with service agencies in their home counties, to monitoring the parents’ emotional health. For example, Ms. Calvert assisted one family who was trying to decide whether to relocate from New Jersey to Pennsylvania and how that might impact their child’s services. Ms. Calvert was able to discuss the differences in services offered to allow the family to make an informed decision. During a follow-up phone call to another family whose child had been diagnosed, Ms. Calvert discovered that the family was residing in a homeless shelter following a house fire, and the behavioral intervention services that the child needed were being withheld following this relocation. Ms. Calvert was then able to coordinate with the early intervention agency to allow these necessary services to continue at the shelter.

Collaboration: Referring hospitals to the program include: Abington Memorial Hospital,; the Hospital of the University of Pennsylvania; and Pennsylvania Hospital. The Neonatal Follow-up Program also provides autism screening and assessment at the Exton Specialty Care Center, which is part of The Children’s Hospital of Philadelphia network. In addition, Ms. Calvert participates in a bi-monthly meeting of autism specialists in the Philadelphia area to discuss relevant policy, resources, and challenges. Strategies for overcoming these barriers are discussed and plans are put into place to better serve families’ needs. This process has provided essential access to a developing consensus of best practices for helping children with autism and their families.

Outcomes and Evaluation: The original grant proposal included seven specific indicators of progress that would be tracked to illustrate the successes described above. For clarity, they are displayed in the table below:

Indicator of Progress measure	Result
Percent of children who failed MCHAT who obtained ADOS evaluation (excluding false positives)	100% of the children who failed the MCHAT were offered an ADOS evaluation from the Neonatal Follow-up Team (excluding the 1 child who could be clinically diagnosed without need for the ADOS); 85% (6 out of 7) of those families returned for the assessment
Percent obtaining ADOS evaluation within one month of failed screening by Neonatal Follow-up Program	83% (5 out of 6) were offered an evaluation within a month, the remaining child was deferred for 3 months for developmental reasons
Percent of children failing MCHAT who are diagnosed with ASD	24%
Percent of families with child who is diagnosed with ASD who receive post-diagnosis counseling from the Program	100%
Parent satisfaction (of educational efforts)	Parents are pleased with reduced intervals between screening and diagnosis, and with the follow-up counseling. They are grateful for the new, service-area-specific resource binders.
Parent satisfaction (of support for obtaining services)	All of our families have been receptive to our social worker's assistance in gaining access to community resources after diagnosis.
Follow-up on diagnosis with supportive phone calls	All families receive multiple calls for support, at the time of initial diagnosis, one month post diagnosis and six months post diagnosis.

Unanticipated Challenges: A challenge in the past year has arisen that threatens the success of the project by limiting the scope of the population that the Neonatal Follow-up Program serves. When children are accepted into the Program as infants they receive both comprehensive developmental assessments by psychologists and complete medical exams by pediatricians and the nurse practitioner. Because psychologists are now required to bill for the developmental assessments, and this assessment is not covered by many families' insurance plans, these infants are not able to be enrolled in the Program from the start. Therefore, these infants cannot be followed by the Program into toddler hood, when autism screening and appropriate follow-up evaluation would occur.

Another unanticipated challenge to providing timely ASD evaluation, diagnosis, and recommendations for treatment is deferred or refused services from a minority of families. This most often appears to result from families' difficulty in contemplating the notion that their child might have such a challenging developmental disability, which results in them deciding not to move forward with follow-up evaluation. The Neonatal Follow-up Program's response to these situations is to attempt to maintain a relationship with the family, encourage the family to seek appropriate interventions for their child regardless of diagnosis, and provide education about ASDs in a manner that is well matched to the families' needs and receptiveness.

Next Steps and Priorities for the Next Year:

Funding: Finding ongoing philanthropic funding to continue to enroll eligible children into the Neonatal Follow-up program based on their high-risk medical history, not based on their ability to pay for behavioral health services.

Expansion of follow-up assessment for ASD: Since we have undertaken the screening and follow-up evaluation of children for ASD, we felt it was necessary to provide the child and family with a more complete battery of tests that included looking for other possible etiologies for this diagnosis. Taking the lead from our Regional Autism Center at CHOP, we are just beginning to do additional medical screening of all patients who receive the diagnosis of ASD. This new protocol includes obtaining appropriate neurological and metabolic testing.

Expansion of educational resources offered to families regarding ASD: We have been researching books that might be of help to families as they learn more about and adjust to their child's new diagnosis. With funding from the Mayer Family Foundation, grant we have recently ordered books to trial with our families.

Long-term follow-up of children diagnosed with ASD: We would like to develop a follow-up questionnaire to administer to our patients about their children's functioning and services received at key developmental transitions after they graduate from our program at age 5. This data would be used to better understand long-term outcomes for our population, and more effectively counsel our families.

Lessons Learned: One of the primary lessons that we have learned over the past year is that providing comprehensive, timely, and helpful evaluation and support services to children with ASDs and their families is a time consuming and expensive endeavor. Nonetheless, the continuity of care that we have been able to provide to our patients through this funding has been an extraordinary asset to our families at every step of the process. At the screening level, having the screening embedded within a larger developmental evaluation allows us to quickly weed out false positive screens and avoid adding the unnecessary stress, time, and financial burden that are associated with pursuing further evaluation without due cause. At the follow-up ASD evaluation step of the process, this funding has allowed us to streamline the process for families by eliminating the need to undergo a complex intake procedure with another agency, have the evaluation completed in a timely manner, and decrease the stress associated with waiting during a period of uncertainty.

At the time of diagnosis, being able to conduct these evaluations within our own Program allows us to use the strength of our already established relationships with our families to provide sensitive feedback and support. In the post-diagnosis period, having the funding to allow our social worker to re-connect with families to make sure that the bridge between the child/family and needed intervention services has been successfully navigated is a critical step not often attempted by agencies providing assessment services. Finally, having the ability to network with other professionals in the field and stay informed about the most current findings pertaining to ASDs allows us to provide the best possible care to our families.



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March 15, 2010

Ms. Barbara J. Pope
The Oscar G. & Elsa S. Mayer Family Foundation
One South Pinckney Street, #312
Madison, WL 53703
USA

Dear Ms. Pope:

Enclosed is the Children's Hospital of Philadelphia's Report of Expenditures for OSCAR
MAYER FOUNDATION for Dr. Bernbaum, Judith. The title of this award is the "NEONATAL
FOLLOW-UP:EARLY IDENTIFICATION OF AUTISM". This report covers the time period of
01/01/09 - 12/31/09.

If you have any questions regarding this report, please contact me at (215) 590-0663 or via
email at changh1@email.chop.edu.

Sincerely,

Helen Chang
Staff Accountant

Enclosure

The Children's Hospital of Philadelphia Research Institute

Report of Expenditures

For the Period 1/1/09 - 12/31/09

Grantor: OSCAR MAYER FOUNDATION
Investigator: Dr. BERNBAUM, Judith
Project Period: 1/1/09 - 12/31/09
Grant Title: NEONATAL FOLLOW-UP:EARLY IDENTIFICATION OF AUTISM
Chop Activity Number: 27300-4248621209

	<u>Budget</u>	<u>Expenses at 6/30/09</u>	<u>Remaining Balance</u>
Salaries	\$ 49,540.00	\$ 38,767.84	\$ 10,772.16
Fringe Benefits	-	10,795.15	(10,795.15)
Supplies	-	-	-
Travel	-	-	-
Miscellaneous Other	460.00	-	460.00
Total Direct Costs	\$ 50,000.00	\$ 49,562.99	\$ 437.01
Indirect Costs	<u>-</u>	<u>-</u>	<u>-</u>
Total Costs	<u>\$ 50,000.00</u>	<u>\$ 49,562.99</u>	<u>437.01</u>


Bethann Kurek
Assistant Director, Research Finance