Inside the Institute

Carolina Institute Scientists Developing Oxytocin Drugs to Improve Social Deficits in Autism

Drs. Cort Pedersen and Sheryl Moy, faculty in the Carolina Institute for Developmental Disabilities, have joined forces with Dr. Michael Jarstfer in the UNC School of Pharmacy to identify compounds that activate human oxytocin receptors. They will test in animal studies whether those compounds have potential therapeutic effects for autism spectrum disorders.

Autism spectrum disorders are characterized by social deficits, difficulty coping with novel situations and repetitive behaviors. Social deficits consist of diminished interest in social interactions and forming close interpersonal relationships that are essential for successful social functioning. Because currently available medications for psychiatric disorders have only minimal benefit in improving these symptoms, there is great need for new pharmacological strategies that may provide more effective treatments.

Continued on page 4

The Writing Skills Development Project: Research Informing Practice

What factors contribute to the development of written expression in the formative elementary school years? Child Neuropsychologist, Stephen Hooper, Ph.D. and his team at the Center for Development and Learning (CDL) -- Project Coordinator Kathleen Anderson, Learning Specialist Donna Yerby, and graduate students Sean Knuth, Amy Childress, Lara-Jean Costa, and Jaclyn Zins -- are looking into answers to this very question.

The Writing Skills Development Project, a four year study currently reaching the end of its third year, is one of only a few longitudinal studies focusing on the develop-

Continued on page 4

Newsletter Highlights

<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structured Teaching</td>
<td>2</td>
</tr>
<tr>
<td>Parent to Parent</td>
<td>2</td>
</tr>
<tr>
<td>From the Desk of the Director</td>
<td>3</td>
</tr>
<tr>
<td>News &amp; Observer feature</td>
<td>3</td>
</tr>
<tr>
<td>Your Support</td>
<td>6</td>
</tr>
<tr>
<td>Announcements</td>
<td>6</td>
</tr>
</tbody>
</table>

At the Carolina Institute for Developmental Disabilities, we support individuals with disabilities and their families by:

- Identifying and applying innovative solutions to complex issues using an interdisciplinary approach
- Studying best practices and translating research into practical applications
- Promoting self-advocacy, leadership, and inclusion by and for individuals with disabilities
- Training world-class leaders and experts in the field of developmental disabilities
Structured Teaching

Structured Teaching, the intervention framework developed by TEACCH, is based upon research findings about the cognitive style and the learning strengths and weaknesses of individuals with autism spectrum disorders (ASD). Often, individuals with ASD have strong visual skills, respond well to having routines, and have powerful interests that can be employed to motivate learning. Auditory processing tends to be a relative weakness, as are organizational skills, social comprehension, and knowing what information in the environment is important to attend to. Structured Teaching is highly individualized, taking each person’s developmental and learning profile into account.

There is a strong research base for using visual supports with learners with ASD. Core elements of Structured Teaching include using visual supports to make the sequence of daily activities predictable and understandable, using visual supports to make individual tasks clear, and structuring the physical environment to clarify expectations and reduce distractions. The framework is comprehensive – it is applied with all ages, from early childhood through adulthood, and for individuals with cognitive delays as well as those who may end up with graduate degrees. Structured Teaching is used in school, home, vocational, and community settings, and in all skill areas, including academic, social, play, communication, daily living, and vocational skills.

Structured Teaching strategies can be used in combination with many therapies and other intervention approaches, making learning and life activities more “autism friendly.” By tailoring intervention to the cognitive and learning style of individuals with ASD, the Structured Teaching approach helps make life more calm and predictable, enhances communication and learning, reduces behavior problems, and promotes independence. TEACCH conducts workshops on Structured Teaching for parents, teachers, and other professionals (go to www.TEACCH.com and click on Training). The website also provides further information about Structured Teaching and has links to articles and publications.

By Gladys Williams, TEACCH

Parent to Parent → Preventing Child Maltreatment

The serious problem of child maltreatment impacts families across the country, and children with disabilities are more than three times as likely to suffer maltreatment as are typically developing children (Sullivan & Knutson, 2000). This disturbing finding suggests that families are in great need of support to cope with the challenge of raising a child who has a disability.

Social support plays an important role in alleviating stress, emotional strain, and isolation of parents of children who have disabilities (Dellve et al., 2006; Plant & Sanders, 2006; Boyd, 2002), and is recognized as a key element for preventing child maltreatment (Fernandez, 2007; Fantuzzo et al., 2006). Because these parents experience more stress and less social support, a program that addresses the need for social support can act as an important tool for preventing child maltreatment (Burrell, Thompson, & Sexton, 1994).

Through a statewide network of affiliated programs, Family Support Network (FSN) uses an established curriculum to prepare Support Parents to offer support to other families in similar circumstances. Such support has proven invaluable and has been identified as a promising practice for this population. (IOM Report, 2005). The Parent-to-Parent program increases protective factors that reduce the likelihood of child maltreatment by increasing parents’ confidence, increasing acceptance of their situation, strengthening their sense of being able to cope (Singer et al., 1999), reducing their anxiety, and enhancing their perceptions of social support (Ireys, Chernoff, Stein, DeVet, Silver, 2003).

Parent-to-Parent offers a parent the chance to be connected with another parent who knows firsthand about the feelings and realities that come with having a child with a disability. According to one parent “The parent match program has given more to my family than we could have ever imagined. Knowing that we are not alone in our struggles has made all the difference.”

By Laura Curtis, Family Support Network
In this issue of the newsletter I would like to welcome Dr. Rob Christian to the Carolina Institute for Developmental Disabilities. Dr. Christian’s role epitomizes what we are trying to accomplish -- with one foot in the CDL and one foot in the TEACCH Program, Rob’s role will be to build a bridge between these two programs to develop statewide medical services for individuals with autism.

Rob is uniquely trained as both a pediatrician and a child psychiatrist. Growing up the son of a well known local pediatrician, R. Meade Christian, M.D., Rob completed an engineering degree at N.C. State, then attended the UNC School of Medicine. Following medical school Rob completed a joint residency program in pediatrics and psychiatry, including a fellowship in child and adolescent psychiatry, at Brown University. Deciding that it was his wife, Jenny’s turn to pursue her career goals after completing her Ph.D. in epidemiology, Rob and his family moved back to Chapel Hill, where his wife joined Glaxo-Smith-Kline to conduct studies in pharmacoepidemiology. An informal conversation between Rob and I by Dr. Gary Mesibov perked his interest in an academic career with a focus on services for individuals with developmental disabilities at the Carolina Institute. A subsequent meeting with Dr. Jim Bodfish sealed the deal when the two realized they shared a strong interest in treatment of the ritualistic-repetitive behaviors seen in individuals with autism and intellectual disabilities.

Dr. Christian trained at Brown University under the mentorship of the late Dr. Henrietta Leonard, one of the preeminent experts in the field of pediatric psychopharmacology and Obsessive Compulsive Disorder. At Brown, he developed a strong interest in both the behavioral and psychopharmacologic treatment of repetitive behaviors making Rob a perfect match for Jim’s clinical and research interests. The two are planning to launch a new behavioral medicine clinic, which combines behavioral and pharmacologic approaches to severe behavior problems in individuals with developmental disabilities, later this spring.

Rob’s primary focus at the Carolina Institute will be in launching a new statewide effort for augmenting medical care for individuals with autism. The plan is only just now being conceptualized but will involve the Carolina Institute providing support to local physicians around the state, in the form of consultation, workshops; and fostering relationships between interested physicians and providers at TEACCH Centers around the state. The specific aim will be to improve management of medical problems and pharmacologic treatment of problem behaviors and psychiatric symptoms in individuals with autism. Dr. Christian is just beginning steps to move this plan into practice, hopefully sometime this fall, by initiating discussions with TEACCH staff and seeking potentially interested physicians around the state.

Please join me in welcoming Dr. Rob Christian. I am certain he will be a wonderful addition to the Carolina Institute.

By Joe Piven, M.D.

---

**Dr. Piven and the Carolina Institute featured in the News & Observer**

Click here to read the Sunday April 13th Tar Heel of the Week article by News & Observer author Jesse DeConto. This article explores the Carolina Institute’s Director, Dr. Piven’s, many accomplishments from his residency at John’s Hopkins to his work bringing together clinicians, researchers, and family advocates today.
Developing Oxytocin Drugs to Improve Social Deficits in Autism continued

Oxytocin is a peptide neurotransmitter found in brain areas that regulate social behaviors, emotions and stress responses. A considerable body of animal research has shown that oxytocin has numerous prosocial effects. Recent studies have found that oxytocin exerts similar effects in human subjects. Other human studies suggest that oxytocin abnormalities may play a role in autism spectrum disorders.

Despite the promising research, oxytocin itself has prohibitive limitations as a drug for these disorders. Oxytocin, like most peptides, is very rapidly destroyed by enzymes in the digestive tract, blood and brain and penetrates very poorly into the brain from the blood. Therefore, oxytocin cannot be taken by mouth and, even when high doses are given by the intranasal or intravenous route, the small fraction of the peptide dose that enters the brain is so rapidly degraded that it does not exert sustained effects. Therefore, Drs. Pedersen and Jarstfer have set out to find non-peptide compounds that activate human oxytocin receptors and are likely to lead to the development of drugs that can be taken orally, penetrate readily into the brain and resist enzymatic break down.

The Carolina Institute for Developmental Disabilities includes the Mouse Behavioral Phenotyping Laboratory, directed by Dr. Moy. This facility specializes in animal testing to measure behavior domains that are relevant to autism, such as social interest, perception of social cues, repetitive behaviors, anxiety and other emotional responses to stress. The Laboratory has also identified mouse strains that exhibit behavioral abnormalities that are similar to autistic symptoms. These behavior tests and mouse strains provide an excellent opportunity to test the potential clinical efficacy of the most potent human oxytocin receptor-activating compounds. Those compounds that increase social interest and social cue perception as well as decrease repetitive behaviors and emotional responses to novelty, will receive the highest priority in future treatment trials in autism spectrum disorder patients. These new drugs may be the first to be truly effective in reversing core symptoms of these devastating developmental disorders.

By Cort Pederson, MD

The Writing Skills Development Project continued

ment of writing, as well as addressing evidence-based interventions in the early elementary school years using a randomized treatment trial. With the help of students (parents and school staff) from all seven elementary schools in Orange County who are participating in the study, this group of researchers at the CDL are examining how children learn to write, how writing is different for children who have learning problems, what factors affect a child’s ability to learn to write, and what strategies may help to improve writing skills.

According to the National Center for Education Statistics (NCES, 2003), only approximately 28% of fourth graders could write at a proficient level or above, 58% wrote at a basic level, and 14% wrote below the basic level. Last year within our state of North Carolina, only 59.8% of fourth graders passed the End-of-Grade writing test for the 2007-08 school year (North Carolina Testing Program, 2008). These data are important because they indicate the national significance of writing problems in elementary education.

Findings from this study should contribute to the development of evidence-based instruction in written language, help to increase an understanding of the cognitive bases of written language, and address the relatively higher prevalence of writing difficulties in the classroom setting by targeting early risk factors and early treatment. This work will also lay the foundation for extension to children with other neurodevelopmental disorders. In addition, these research efforts are being conducted in the school setting and so will have immediate applications to evidence-based educational practices.

The Department of Education Institute of Education Sciences is providing funding for this project. Click here for more information.

By Keath Low, MA
Leadership

Announcements:

- **April is Autism Awareness Month:**
  - Order online from Papa John’s until April 26th and 10% of the purchase price will be donated to TEACCH. Applies to Chapel Hill, Raleigh, and Fayetteville. [Click here](#) for more info.
  - Participate in Autism awareness events like the Black Balloon Movie Event and Autism Awareness with the Durham Bulls. [Click here](#) for more info.

- **New Williams Syndrome Clinic at the CDL:**
  - The Williams Syndrome Clinic provides a comprehensive interdisciplinary evaluation of your child’s or adolescent’s psychological, speech and language and educational functioning linked to intervention planning in order to optimize school and social experiences in all settings. The clinic is designed for individuals who already have a diagnosis of Williams Syndrome. [Click here](#) for more info.

- **30th Annual TEACCH Conference- Reflections on 30 years of Autism Research and Practice:**
  - Don’t miss this landmark conference designed for teachers, psychologists, parents, researchers, physicians, allied health professionals, and other interested in the field of Autism. [Click here](#) for more information.

- **Acting Class for persons with Developmental Disabilities:**
  - The ArtsCenter and Extraordinary Ventures are teaming up to offer a theater workshop for persons with developmental disabilities, ages 15 years old and up. Lisa Levin Klein, a local actress and improvisational performer will be teaching the seven-week acting class. Students will be able to be accompanied by their care providers. [Click Here](#) for more information.

- **Leadership Grant at CDL Supports Collaboration with Other MCH-Funded Universities at Conference for Early Hearing Detection and Intervention:**
  - CDL is home to one of three national center grants for Leadership in Communication Disorders, funded by HRSA/MCH. Together with our counterparts at Vanderbilt and Utah State University, the grants in the 2008-2013 cycle focus on the preparation of future leaders from the disciplines of audiology and speech-language pathology to serve newly identified infants and young children with hearing loss and their families. Earlier this year the three leadership programs worked to extend an invitation to LEND faculty and students from other universities to participate in the annual conference for Early Hearing Detection and Intervention (EEDI) held in Dallas, Texas, March 9-10.

Send us your comments:

We would love to hear from you if you have comments about our newsletter, ideas for potential articles, or if would like to be added to our newsletter list! Drop us a line at info@cidd.unc.edu.

Carolina Institute for Developmental Disabilities
www.cidd.unc.edu

Your Support

For more than 40 years, the programs of the Carolina Institute for Developmental Disabilities have provided innovative, high-quality clinical, research, and training, activities supporting individuals with developmental disabilities.

The population of our state and nation is growing, and the disability community is growing as well. Children are being diagnosed with developmental disabilities such as autism at an exponential rate. Often, families dealing with a loved one with a disability can feel overwhelmed and need a place to find real answers. Through innovative research that improves practice and enhances education, we will find solutions.

Now, more than ever, we need well-trained practitioners, teachers, and researchers. State funds pay only part of the costs to recruit and retain the best faculty and support the unique training and programs that are the hallmarks of the Carolina Institute for Developmental Disabilities experience. It is private funds that sustain and enhance these extraordinary opportunities for students, patients, families, and faculty. We can’t do it without you!

Philanthropic support is essential to the growth of the Carolina Institute for Developmental Disabilities and its goal of improving the quality of life for people with developmental disabilities across North Carolina and throughout the country.

A gift to the Carolina Institute for Developmental Disabilities is an investment in the lives of thousands and in the future of our communities. Join us by giving today.

To make a donation by credit card, please visit the Medical Foundation of North Carolina’s gifting page and choose “Carolina Institute for Developmental Disabilities.” [Click Here](#).

To make a cash donation, please send your check to: The Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, Office of Development, CB# 3366, Chapel Hill, NC 27599-3366.

Contact: Susannah Hough at (919) 966-5610 or Susannah_hough@med.unc.edu to discuss your giving options.