

**From:** Case Management Society of New England <cmsne@comcast.net>  
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## The Facilitator

A bimonthly publication of the Case Management Society of New England - June July 2011

### President's Message



Summer has finally arrived in New England bringing new life and energy to our area which I am also feeling after spending this past week in San Antonio, Texas attending CMSA's 21<sup>st</sup> Annual Conference. It's such a wonderful experience to be with more than 2,300 case managers hearing about their work while attending numerous educational programs covering a wide variety of topics. It was also humbling to be able to spend that much time with hundreds of our military men & women who were also able to attend this conference. I thank you one and all for what you have done for our

country.

Pre-conference sessions included special programs for the military, the CCM Prep-Course and Leadership programs for CMSA chapter leaders. Monday evening was the Chapter Leaders mixer where leaders from many of the more than 70 CMSA Chapters gathered to socialize and exchange "pins" specially designed for this event and showcasing their chapter. Be sure to look for CMSNE's new chapter pin which is available for purchase. Terri Treiger, President of CMSA (and CMSNE member) opened the day on Tuesday with the Annual Meeting, acknowledging hundreds of first time conference attendees and reviewing CMSA's accomplishments over the past year during her term as President, including development of the Case Management Resource Toolbox, CMSA's Career & Knowledge Pathways and the release of the first print of CMSA's new magazine, CMSA Today. Terri then continued her year in review outlining the mission, vision & strategic plan for CMSA and discussing the issues facing case managers today. Throughout the conference Terri's message was clear: "Case Management is a symphony, not a solo" and we all must work together to achieve our goals.

The opening main session on Tuesday was heartwarming, with a presentation from Suzanne Mintz discussing the role of the family caregiver and Catherine Mullahy discussing the caring heart of the case

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manager. Then it was off to Knibee Ranch, a working Texas cattle ranch for an evening of music, dancing and a live rodeo (dust and heat no extra charge!!). Everyone had a great time and the mood was set for 3 more days of education and networking. Session topics included a wide range of medical issues, new and emerging treatment approaches, ethics, best practices and a multitude of sessions designed to ensure our continued successes as case managers.

Wednesday CMSNE was acknowledged during the Chapter President's Council Meeting for our outstanding efforts in Technology and Chapter Membership Development. We gained 28 new members during this past year while the Detroit City Chapter boasted 430 members for this single city chapter. The CPC Council then discussed ways to mentor new and smaller chapters in continuing their growth and development. The main session that day was Bill Crounce, MD reviewing how *eHealth Changes the Game for CM Professionals & Their Patients*. Wednesday was also the grand opening of the exhibit hall. Hundreds of vendors/exhibitors were there sharing their knowledge, services and products designed to assist case managers in everything they do. CMSA was proud to announce that there were more than 50 new exhibitors, which I found very exciting!

Thursday started off with Breakfast Symposiums and then it was time for the CMSA Awards Event. I was proud to be a member of CMSNE when the winner of the award for Service Excellence was announced as our own Carol Gleason. She truly epitomizes the excellence of case management that we all hope to achieve.



CMSNE was also recognized as the winner of the Award for Excellence in Technology for our chapter website. Many of the other Chapter Leaders had commented on how they were utilizing our web site as a resource and how beneficial they found it. I want to give a resounding thank you to our Executive Director, Maureen Ferguson for her years of hard work involved in developing and maintaining the web site. This award would not have been possible without her dedication to our chapter. It was also exciting to see how many individuals submitted posters for review at the conference. There were so many that they had to divide them up, presenting half on Thursday and the remainder on Friday.

With the closing session on Friday and the exchange of the Presidential Gavel, I was reminded that no matter how hard we as case managers work we can only scratch the surface of the healthcare system, hoping to meet all the needs of the individuals we serve. We face a multitude of issues impacting our efforts, including an aging population (not only in the clients/patients we serve but ourselves as well), spiraling healthcare costs, limited/unavailable resources, fragmentation in the profession and issues that are much more medically & behaviorally complex, just to name a few. It is through attending events such as this conference and our own Annual Conference scheduled for September 29<sup>th</sup> & 30<sup>th</sup> that we can continue to

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CMSNE Annual Conference -  
9/29 - 9/30/11

***Bridging Gaps - Creating Opportunities for New Models of Care***

[Exhibitor Prospectus now available](#)

Brochure available  
mid July.

### Special Thanks to our CMSNE Corporate Sponsors

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expand our knowledge and become part of the "symphony" of case management moving beyond the single voice of the soloist.

Nancy Benoit, RN, CRRN, CCM, President 2010-2011

## Nominating Sought for CMSNE Board of Directors 2011-2012

Nominations are currently being sought for the 2011-2012 CMSNE Board of Directors.

Positions currently open for nominations include:

**Vice President**

**Secretary**

**Treasurer**

**Directors at Large (3)**

**Chair/Co-Chairs of ME, NH, RI and Central/Western MA Extension**

\* job descriptions can be found at: <http://cmsne.org/resources/> under "J"

We currently have one individual for each of the position, except for the Central/Western MA Extension, without a representative from this area we will not be able to continue offering educational programming in that region. Please consider running for a position you will find your experience both rewarding and fun. For additional information contact [Susan Madden](#) or the [chapter office](#). Nominations are due to the chapter office no later than 7/15/11. Nominees should complete [this form](#) and return them and a photo of themselves to the chapter office.

Election will be held from 8/1 - 8/15/11.

## CMSNE MEMBER WINS NATIONAL AWARD FOR SERVICE EXCELLENCE



**Carol A. Gleason MM, RN, CRRN, CCM, LRC, BCPC** was awarded the **2011 Award for Service Excellence** at the 21<sup>st</sup> Annual CMSA Conference in San Antonio, Texas on June 16, 2011. Carol, who works as the RN Float Coordinator at Brigham & Women's Hospital in Boston, MA, was described as a "true visionary in how clinical practice improves when professionals influence Public Policy through her teaching of fellow case managers, co-workers and the general public." Her commitment & dedication to her work as the Vice-Chair of CMSA's Public Policy Committee is evident in everything she does, not only with her presentations, poster sessions and mentoring of case managers new to this arena, but her enthusiasm and winning smile portray an infectious energy & desire to become involved, leading everyone who meets her wanting to make a difference as Carol obviously does. Carol was also

[Kindred](#)

[New England Sinai Hospital](#)

[Spaulding Rehab Network](#)

[Whittier Rehab Hospital](#)

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recognized by the physicians within the Brigham & Women's Hospital system, winning the 2010-2011 Internal Medicine Housestaff Nursing Recognition Award.

## A Few of My Favorite Things CMSA San Antonio Conference



Front row: Nancy Benoit, Carol Gleason  
Back row: Sandra Lowery, Susan Madden, Teri Treiger,  
Margaret St. Coeur and Dolores Burke

The National CMSA Conference in San Antonio was a fabulous experience! I would like to share some my "favorite things".

- Carol Gleason was awarded the 2011 CMSA National Service Excellence Award! This is one of the most prestigious awards in our field. Carol was nominated by our chapter for this award because of her outstanding work in the field of Case Management including grass roots Case Management, Chapter Leadership and most recently her work in public policy, just to name a few.
- Our chapter won the award for Chapter Excellence for Technology. Nancy Benoit and Sue Madden proudly accepted the award.
- Our own Teri Treiger, President of CMSA, presided over the business meeting, award ceremony and other festivities. She was there at the entrance to Knibbe Ranch to greet each of us on arrival in her pink fringe cowboy hat! (For real!)
- The breakout sessions and key notes offered lots of great learning. I was particularly touched by Suzanne Mintz's presentation on "Strengthening the Family Caregiver Advocacy Role in Case Management". She gave voice to the perspective and issues of the caregiver that are so important for Case Managers to remain aware of and sensitive to.
- It was wonderful to network and share time with colleagues in the beautiful city of San Antonio.

Dolores Burke, CMSNE Secretary

## CMSNE Annual Conference News



***Bridging Gaps***  
***Creating Opportunities for New Models of Care***

Thursday, September 29 and Friday, September 30, 2011  
DCU Center Convention Center, Worcester, MA

As we begin to plan our summer outings and vacations, it is hard to think about fall activities, but the CMSNE Annual Conference: ***Bridging Gaps: Creating Opportunities for New Models of Care*** is just around the corner. The conference committee has been busy confirming keynote speakers, breakout and poster sessions.

As case managers, all of us work with a number of providers/vendors that offer individuals we serve a variety of services to meet their healthcare needs. Why not share these resources with others and have them exhibit at the annual conference? If you refer a vendor and they do exhibit, you will receive a \$20 discount on your registration to attend the conference, just be sure to notify the CMSNE office that you referred a specific vendor or have them notify us on their application that you made the referral. It is through our vendors that we are able to keep the costs of the seminar so low. Download the Exhibitor Prospectus from the CMSNE website.

Look for the conference brochure to be available by late July. Register early to ensure you don't miss out on your favorite topics such as Vitamin D deficiency, Obesity, Behavioral Medicine, and Lobbying. Our special session will be on Autism. We are also excited to have Loretta Laroche speaking. Hers will be a wonderful light-hearted session to revitalize all of us. Visit our web page for additional information.

The Exhibitors Prospectus is also available. We hope to have our regular vendors return and we welcome new vendors. Reaching out to new vendors will ensure we can continue to bring quality programs to our membership and meet the client needs of a variety of case management settings. If you are reluctant to contact someone directly, pass on their contact information and the conference committee members will be happy to contact him or her for you. [Download a copy of the Exhibitor Prospectus here.](#)

For additional information contact the CMSNE Chapter office at [CMSNE@comcast.net](mailto:CMSNE@comcast.net)

[Susan Madden](#) and [Sheila K. Bennion](#), Co-chairs CMSNE Annual Conference

**A Call to Action - Letter Writing Campaign RE:  
Nurse Licensure Compact in Massachusetts**



The CMSNE Public Policy Committee is planning to launch a letter writing campaign in August in support of Nurse Licensure Compact (NLC) legislation in Massachusetts after learning that a Public Hearing on NLC legislation before the Joint Committee on Public Health is scheduled for September at the State House, Boston, MA. The bill's (H.1493) current petitioners are House Representatives Kay Khan (Newton), Denise Provost (Somerville) and Jennifer Benson (Lunenburg). (source: [www.malegislature.gov/](http://www.malegislature.gov/))

### **What is NLC Legislation?**

According to the National Council of State Boards of Nursing (NCSBN), NLC legislation allows nurses to have one license (in the state of residency) and be able to practice in other Compact states (physically, telephonically and electronically) subject to each state's practice law and regulation. (source: [www.ncsbn.org/nlc](http://www.ncsbn.org/nlc))

### **Why is NLC Legislation important to Nurse Case Managers?**

Use of telecommunication and e-health technology in case management has risen to support the growing mobile patient population. This places nurse case managers at risk for unlawful nursing practice when services are provided to patients in states where a license is not held, thus crossing state lines. It is also costly and burdensome for nurse case managers to hold licenses in multiple states.

### **What are the benefits of NLC Legislation?**

NLC promotes lawful nursing practice, continuity of care, compliance with laws governing nursing practice, and facilitates the state's responsibility to protect the public's health and safety. As of 2010, 24 states have adopted NLC legislation which allows for nurses to practice safely within Compact States. New England States Maine, New Hampshire and Rhode Island have already adopted NLC Legislation.

### **What is CMSNE doing to support NLC Legislation?**

1. The Public Policy Committee is launching a Letter writing campaign to Massachusetts Legislators lobbying for their support in adopting NLC legislation in Massachusetts.
2. CMSNE is developing a webpage containing information on NLC legislation, with contact information on Massachusetts Legislators and template letters supporting NLC in Massachusetts. Emails can be sent directly to MA Legislators and Petitioners of the bill. Letters can be downloaded, signed and sent directly to MA Legislators. (webpage available at [www.cmsne.org](http://www.cmsne.org) by 8/1)

### **What can YOU do to help?**

1. Participate in the letter writing campaign in August by downloading, signing and sending the NLC support letter to MA state Representatives and Senators.
2. Engage your colleagues to do the same.
3. Engage your colleagues to sign a petition which can be sent directly to the Chair of the Joint Committee on Public Health, Commonwealth of Massachusetts.

### **Thank you for your support!**

CMSNE Public Policy Committee Members  
Patricia Noonan, RN, MBA, CCM  
Susan Bartlett, LCSW, CRC  
Catherine Mimnaugh, RN, MBA/HCM, CCM  
Jenny Quigley-Stickney, RN, MA, MSN, /MHA, CCM  
Linda Dillon-Rydman, RN, BSN

**Public Policy News**



### **Public Policy Summit Update**

On April 5<sup>th</sup> and 6<sup>th</sup>, Catherine Mimnaugh and I attended CMSA's Public Policy Summit held in Washington, DC, sponsored by the CMSNE chapter. The two-day Summit program titled "Raising the Importance of Quality Care from the Hill through Education for Case Managers and Legislators" was an exciting, memorable experience for all those that attended. The summit provided both new attendees as well as seasoned attendees the opportunity to network with CMSA's Public Policy Committee and meet with case management liaisons from the various State chapters. The Summit also provided an excellent opportunity for education on the current health policy landscape. Day one kicked off with breakfast at George Washington University's Jack Morton Auditorium followed by a panel discussion on health care reform led by experts presenting on Health Reform, GWU public policy resources and programs, the progress made by the National Transitions of Care Coalition (NTOCC) and the Case Management Model Act history and background. We were also educated on the role media plays in shaping health care policy and health reform's impact on case management. All the Summit participants were placed in groups led by team captains who prepared and accompanied the groups to the legislative appointments.

Day two included a full day of legislative appointments on the Hill which gave us an opportunity to talk with our legislators on the importance of case management and the role case managers play in care coordination, transitions of care, cost containment and quality outcomes. We were able to educate our Legislators on the Case Management Model Act, the Standards of Practice, NTOCC and share CMSA's materials. Our group, led by Carol Gleason, had the opportunity to meet with Legislative Assistants to Senators: John Kerry (MA), Kelly Ayotte (NH), Jeanne Shaheen (NH), Olympia Snowe (ME), Sheldon Whitehouse (RI) and US Representative John Tierney (MA). We were also able to provide information to Senator Brown's (MA) office. The highlight of our Summit was being invited to breakfast and speaking with Senator Jeanne Shaheen. Overall, there were 150 Legislative appointments held by case managers lobbying on the Hill as a result of the Summit and I was very grateful to be given the opportunity. The Public Policy Summit experience was a very positive one and I look forward to next year's Summit with enthusiasm as we continue to advocate for case management and recruit sponsorship for the Case Management Model Act with the ongoing efforts that are underway within our local chapter.

Submitted by  
Patricia Noonan, RN, MBA, CCM  
CMSNE Public Policy Committee  
CMSA Public Policy Liaison

**Rebuilding Lives: New Advances in  
Trauma Rehabilitation Conference**

The CMSNE chapter was asked by Spaulding Rehabilitation Network to attend their first Trauma Rehabilitation conference held in Boston at The Hyatt Harborside in June. This networking opportunity offered the chapter the ability to educate case managers in both acute and rehab case management about the importance of certification, discuss advantages of chapter membership and market our educational programs available throughout the chapter.

Some of the conference highlights were Dr. Hasan Alam, Director of Research and Trauma at Mass General who provided an overview of emergent and acute trauma care and the importance of developing accountable care organizations. The second speaker Dr. Ross Zafonte focused on Research in Rehabilitation: Where are we going and how are we getting there? This presentation examined the emergence of technology, pharmacology and tailoring therapy programs to patient centered care.

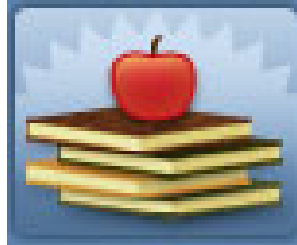
The afternoon had many exciting breakout sessions, some of which members will have the opportunity to see at the CMSNE annual conference in September. Featured presenters were Dr. Giacino speaking about Disorders of Consciousness and Dr. Christopher Carter speaking about Disability Adjustment. Case Management Along the Continuum was presented in a panel format monitored by the Director of Case Management at Spaulding and representatives of case management from acute care, spinal cord rehabilitation and insurance case management. This presentation focused on case management teamwork and utilization of resources across the continuum for transitioning a spinal cord patient to the community.

Special thanks to [Spaulding Rehab Network](#) for providing the chapter with an opportunity to share information about our organization, as well as a rewarding educational experience.

[Jenny Quigley-Stickney, RN, MSN, MHA, CCM](#), Vice President of CMSNE

## Scholarship/CMOY

Would you like to attend the next CMSA Conference in San Francisco in June 2012? Or our own CMSNE Conference in Worcester, MA in September 2011? Looking for financial assistance to do this? Active members of CMSNE are entitled to receive a scholarship of up to \$500 to defray their expense of an educational program. [Please refer to the chapter website for the process and application.](#)



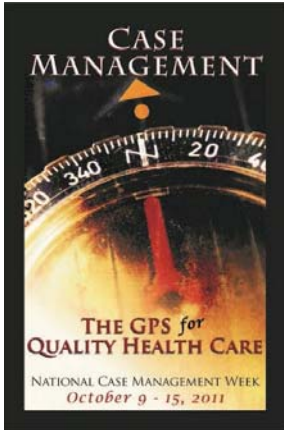
On the webpage you'll find some of the events members have used scholarship funds for to further their education.

There are many among you who would qualify for the Case Manager of the Year Award! Why not nominate a co-worker for this prestigious award? Look around you and nominate as many as you would like! Many of our colleagues go above and beyond and this is one way to give them much-deserved recognition. Postmark is required by August 31, 2011. [You can download a copy of the CMOY/Recognition of Excellence Application from the chapter website](#)

Keep in mind that your support of raffle ticket sales, the purchase of the jeweled name badge holders available at conferences, and the new CMSNE lapel pins helps to keep these programs funded!

The scholarship committee is soliciting donations of prizes to supplement the CMSNE Annual Scholarship Raffle. Those interested in donating items should contact the chapter office directly.

## Celebrate Case Management Week Case Management - A GPS for Quality Health Care



CMSNE is excited to celebrate Case Management Week October 9-15th. This is a wonderful opportunity to share your profession with other colleagues, patients and the public. Please take a moment to look online at [www.cmsa.org](http://www.cmsa.org) for celebration ideas.

Each extension of CMSNE will offer a program for members and non-members to attend for networking and learning. A small gift will be given and everyone in attendance will have an opportunity to win a free membership for one year with CMSA/CMSNE.

Please watch your email for a printable poster to share with your colleagues. I am encouraging our members to contact us with your celebration ideas so that we can share with others in the upcoming newsletters.

## NH Extension News

Hello from NH

The NH Extension will take a short break from hosting educational seminars for the summer but we won't take a break from getting our fall and winter programs planned and organized.

This year we were lucky to have so many sponsors for programs and speakers that we were able to offer a variety of programs both day and evening on many different topics. Attendance to our programs in NH has greatly increased from several years ago, when programs were being canceled due to low attendance. We were happy to welcome many non members and hope that the exposure to the wonderful programs offered here in NH will encourage them to join. Our focus has been on offering topics that will be helpful to all case managers, not only in differing specialties but also in your personal life. We hope to continue this positive trend in the programs we offer to our growing audience.



For the fall we already have 3 exciting programs planned with more on the way! We have answered the request of our case managers in the Lebanon and VT border areas and are offering a program at DHMC on 9/12 that will have an occupational health focus. On 9/16 we will host a program with the NH PT Association on physical therapy coding and billing practices. Due to the high demand we have also booked a full day program to be held in the first week of November with topics to include pediatric behavioral issues and infectious diseases as well as 2 additional

topics we are currently finalizing. We have been receiving great feedback on the variety of programs we are offering and will continue to take the suggestions of membership for future programs.

We hope everyone enjoys the summer sunshine and we will see you all in the fall!

[Kari Pillsbury](#) and [Marta Robbins](#)

## Maine Extension News



Summer is in full swing and the extension kicked it off on a rainy day in Augusta with the annual day-long conference, *Medical Marijuana, Safety, Risk and the Law*.

While attendance wasn't what we had hoped, everyone seemed to appreciate the very informative topic with Dr. Howard Jones, Certified Occupational

Health Physician, David Ciullo, Career Management Associates and Peter D. Lowe, Esq., Brann & Isaacson presenting. The extension is looking at relocating the conference and perhaps changing the date for next year.

Suggestions from the membership are appreciated!

August 8, 2011 is the date for the next meeting at Apria HealthCare in Yarmouth. Deborah Fischer, RN, form Lakeview NeuroRehab at Home will be presenting on ***Homecare for the Brain Injured Patient***.

The annual dinner recognizing Case Management Week will again be held at the Harraseeket Inn in Freeport on October 11, 2011. Gregg Lubinsky, RPh, FASCP, CCP will be presenting ***Case Management of Hypertension: Identifying Appropriate Patients for Intervention***. Reservations MUST be made by October 1 to CMSNE either on the website or by phone. The Inn will be unable to accommodate walk-ins that evening. Put the date on your calendar and make your reservation when the meeting flyer arrives, don't delay!

CEUs for RN & CCMs will be available for both programs.

We are open to any suggestions for meeting topics, locations, or formats! Please don't hesitate to contact either one of us as we prepare for 2012 programs. Have a great summer!

[Arline Waecker](#) and [Judy Underwood](#), Maine Extension Co-Chairs

## Rhode Island Extension News

Hello to all. Here's hoping that you are having a lovely spring and are planning for a safe and sunny summer. Mark your calendars for our upcoming events.

Home Care New England will sponsor a program on Thursday, August 11th. The speaker, Bob Messinger, from Invacare, will be presenting information on the topic of **Long Term Oxygen Therapy - Improving Patient Outcomes**. This program will be held at Chelo's, on Post Road, near the airport.



The program in September will be held at Neighborhood Health Plan of Rhode Island (NHPRI). The date for the program is Thursday, September 15<sup>th</sup>. The topic for this program is the social initiative for CMSNE. Dr. Todd Levine will speak on **Behavioral Assessment of Children with Autism Spectrum Disorder**. This program is co sponsored by NHPRI and Beacon Health Strategies. Please note that there will be no dinner meal at this program. Snacks and water will be provided. Please plan accordingly.

October's meeting will be held at Kent Regency, a skilled nursing and rehabilitation facility operated by Genesis. The date is set for October 13<sup>th</sup>. Care Point Partners will sponsor the program. The topic is **Ethics on the Frontline**. Please join us for our special evening to celebrate Case Management Week.

November will find us back at Chelo's on Thursday, November 3<sup>rd</sup> the Lap-Band AP System is sponsoring the presentation by Dr. Adam Glasgow. He will deliver information on **The Impact of Obesity and the Value of Treatment**.

The autumn will be filled with these educational programs and networking opportunities. Mark your calendars and bring a friend. Check the website for further details. We look forward to seeing you there! Enjoy the sunshine of the next few months! We will see you in August!

Thank you to all of our speakers and sponsors! We could not do this without you!

[Rose](#) and [Gina](#), Co-Chairs RI Extension

## Western MA Extension News



Although we in the early summer, enjoying the BBQ's and looking forward to vacations, it is never too early to think about Fall programs for our Western Mass Extension.

We had some great programs this past Winter and Spring, including a well attended full day program at the Mass Mutual Conference Center. Thank you to all our sponsors and please think of them with your referrals.

Case Management Week is planned with CMSNE and each extension will be providing an educational program, a raffle of a free membership for the upcoming year and gift for attendees of the programs. We encourage our members to bring a co-worker or friend to attend as its a great way to network, obtain the needed CEU's and have a wonderful dinner out. Please keep an eye out on the CMSNE website for a date, time and place of our Western Mass evening program on the calendar.

We are also in the process of scheduling an educational program/dinner in the Fall in combination with the CT Chapter. The topic will be on Hypertension and is in the early stages of development.

Finally, CMSNE already has the planned annual program in Worcester, MA September 29th and 30th. As always, its a well attended program, with a diverse program for all to enjoy. Registration is coming up soon, so please sign up early to save a spot.

As co-chair of the Western Mass Extension, I am notifying the members that I will not be going for re-nomination. I will be an "involved member". My encouragement to each member is to become involved, either on a committee, the board, or even involvement in the Western Mass Extension so the programs can remain an option for our area to attend. Please feel free to contact me at anytime to discuss potential opportunities for your participation as a member of CMSNE.

Have a safe and happy summer.  
Kim

[Liz Decker](#) and [Kim Ferris](#), CMSNE, WMA Extension Co-Chairs

## CMSNE Social Initiative - Autism

### What is Asperger syndrome?

Asperger syndrome (AS) is a developmental disorder that is characterized by: <sup>1</sup> limited interests or an unusual preoccupation with a particular subject to the exclusion of other activities

- repetitive routines or rituals
- peculiarities in speech and language, such as speaking in an overly formal manner or in a monotone, or taking figures of speech literally
- socially and emotionally inappropriate behavior and the inability to interact successfully with peers
- problems with non-verbal communication, including the restricted use of gestures, limited or inappropriate facial expressions, or a peculiar, stiff gaze
- clumsy and uncoordinated motor movements

AS is an autism spectrum disorder (ASD), one of a distinct group of neurological conditions characterized by a greater or lesser degree of impairment in language and communication skills, as well as repetitive or restrictive patterns of thought and behavior. Other ASDs include: classic autism, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS).

Parents usually sense there is something unusual about a child with AS by the time of his or her third birthday, and some children may exhibit symptoms as early as infancy. Unlike children with autism, children with AS retain their early language skills. Motor development delays - crawling or walking late, clumsiness - are sometimes the first indicator of the disorder.

The incidence of AS is not well established, but experts in population studies conservatively estimate that two out of every 10,000 children have the disorder. Boys are three to four times more likely than girls to have AS.

Studies of children with AS suggest that their problems with socialization and communication continue into adulthood. Some of these children develop additional psychiatric symptoms and disorders in adolescence and adulthood.

Although diagnosed mainly in children, AS is being increasingly diagnosed in adults who seek medical help for mental health conditions such as depression, obsessive-compulsive disorder (OCD), and attention deficit hyperactivity disorder (ADHD). No studies have yet been conducted to determine the incidence of AS in adult populations.

### **Why is it called Asperger syndrome?**

In 1944, an Austrian pediatrician named Hans Asperger observed four children in his practice who had difficulty integrating socially. Although their intelligence appeared normal, the children lacked nonverbal communication skills, failed to demonstrate empathy with their peers, and were physically clumsy. Their way of speaking was either disjointed or overly formal, and their all-absorbing interest in a single topic dominated their conversations. Dr. Asperger called the condition "autistic psychopathy" and described it as a personality disorder primarily marked by social isolation.

Asperger's observations, published in German, were not widely known until 1981, when an English doctor named Lorna Wing published a series of case studies of children showing similar symptoms, which she called "Asperger's" syndrome. Wing's writings were widely published and popularized. AS became a distinct disease and diagnosis in 1992, when it was included in the tenth published edition of the World Health Organization's diagnostic manual, *International Classification of Diseases (ICD-10)*, and in 1994 it was added to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, the American Psychiatric Association's diagnostic reference book.

### **What are some common signs or symptoms?**

The most distinguishing symptom of AS is a child's obsessive interest in a single object or topic to the exclusion of any other. Some children with AS have become experts on vacuum cleaners, makes and models of cars, even objects as odd as deep fat fryers. Children with AS want to know everything about their topic of interest and their conversations with others will be about little else. Their expertise, high level of vocabulary, and formal speech patterns make them seem like little professors.

Children with AS will gather enormous amounts of factual information about their favorite subject and will talk incessantly about it, but the conversation may seem like a random collection of facts or statistics, with no point or conclusion.

Their speech may be marked by a lack of rhythm, an odd inflection, or a monotone pitch. Children with AS often lack the ability to modulate the volume of their voice to match their surroundings. For example, they will have to be reminded to talk softly every time they enter a library or a movie theatre.

Unlike the severe withdrawal from the rest of the world that is

characteristic of autism, children with AS are isolated because of their poor social skills and narrow interests. In fact, they may approach other people, but make normal conversation impossible by inappropriate or eccentric behavior, or by wanting only to talk about their singular interest.

Children with AS usually have a history of developmental delays in motor skills such as pedaling a bike, catching a ball, or climbing outdoor play equipment. They are often awkward and poorly coordinated with a walk that can appear either stilted or bouncy.

Many children with AS are highly active in early childhood, and then develop anxiety or depression in young adulthood. Other conditions that often co-exist with AS are ADHD, tic disorders (such as Tourette syndrome), depression, anxiety disorders, and OCD.

### **What causes AS? Is it genetic?**

Current research points to brain abnormalities as the cause of AS. Using advanced brain imaging techniques, scientists have revealed structural and functional differences in specific regions of the brains of normal versus AS children. These defects are most likely caused by the abnormal migration of embryonic cells during fetal development that affects brain structure and "wiring" and then goes on to affect the neural circuits that control thought and behavior.

For example, one study found a reduction of brain activity in the frontal lobe of AS children when they were asked to respond to tasks that required them to use their judgment. Another study found differences in activity when children were asked to respond to facial expressions. A different study investigating brain function in adults with AS revealed abnormal levels of specific proteins that correlate with obsessive and repetitive behaviors.

Scientists have always known that there had to be a genetic component to AS and the other ASDs because of their tendency to run in families. Additional evidence for the link between inherited genetic mutations and AS was observed in the higher incidence of family members who have behavioral symptoms similar to AS but in a more limited form. For example, they had slight difficulties with social interaction, language, or reading.

A specific gene for AS, however, has never been identified. Instead, the most recent research indicates that there are most likely a common group of genes whose variations or deletions make an individual vulnerable to developing AS. This combination of genetic variations or deletions will determine the severity and symptoms for each individual with AS.

### **How is it diagnosed?**

The diagnosis of AS is complicated by the lack of a standardized diagnostic screen or schedule. In fact, because there are several screening instruments in current use, each with different criteria, the same child could receive different diagnoses, depending on the screening tool the doctor uses.

To further complicate the issue, some doctors believe that AS is not a separate and distinct disorder. Instead, they call it high-functioning autism (HFA), and view it as being on the mild end of the ASD spectrum with symptoms that differ -- only in degree -- from classic autism. Some clinicians use the two diagnoses, AS or HFA, interchangeably. This makes gathering data about the incidence of AS difficult, since some

children will be diagnosed with HFA instead of AS, and vice versa.

Most doctors rely on the presence of a core group of behaviors to alert them to the possibility of a diagnosis of AS. These are:

- abnormal eye contact
- aloofness
- the failure to turn when called by name
- the failure to use gestures to point or show
- a lack of interactive play
- a lack of interest in peers

Some of these behaviors may be apparent in the first few months of a child's life, or they may appear later. Problems in at least one of the areas of communication and socialization or repetitive, restricted behavior must be present before the age of 3.

The diagnosis of AS is a two-stage process. The first stage begins with developmental screening during a "well-child" check-up with a family doctor or pediatrician. The second stage is a comprehensive team evaluation to either rule in or rule out AS. This team generally includes a psychologist, neurologist, psychiatrist, speech therapist, and additional professionals who have expertise in diagnosing children with AS.

The comprehensive evaluation includes neurologic and genetic assessment, with in-depth cognitive and language testing to establish IQ and evaluate psychomotor function, verbal and non-verbal strengths and weaknesses, style of learning, and independent living skills. An assessment of communication strengths and weaknesses includes evaluating non-verbal forms of communication (gaze and gestures); the use of non-literal language (metaphor, irony, absurdities, and humor); patterns of inflection, stress and volume modulation; pragmatics (turn-taking and sensitivity to verbal cues); and the content, clarity, and coherence of conversation. The physician will look at the testing results and combine them with the child's developmental history and current symptoms to make a diagnosis.

#### **Are there treatments available?**

The ideal treatment for AS coordinates therapies that address the three core symptoms of the disorder: poor communication skills, obsessive or repetitive routines, and physical clumsiness. There is no single best treatment package for all children with AS, but most professionals agree that the earlier the intervention, the better.

An effective treatment program builds on the child's interests, offers a predictable schedule, teaches tasks as a series of simple steps, actively engages the child's attention in highly structured activities, and provides regular reinforcement of behavior. This kind of program generally includes:

- social skills training, a form of group therapy that teaches children with AS the skills they need to interact more successfully with other children
- cognitive behavioral therapy, a type of "talk" therapy that can help the more explosive or anxious children to manage their emotions better and cut back on obsessive interests and repetitive routines
- medication, for co-existing conditions such as depression and anxiety
- occupational or physical therapy, for children with sensory integration problems or poor motor coordination
- specialized speech/language therapy, to help children who have trouble with the pragmatics of speech - the give and take of normal

- conversation
- parent training and support, to teach parents behavioral techniques to use at home

### **Do children with AS get better? What happens when they become adults?**

With effective treatment, children with AS can learn to cope with their disabilities, but they may still find social situations and personal relationships challenging. Many adults with AS are able to work successfully in mainstream jobs, although they may continue to need encouragement and moral support to maintain an independent life.

### **What research is being done?**

The National Institute of Neurological Disorders and Stroke (NINDS) is one of the federal government's leading supporters of biomedical research on brain and nervous system disorders. The NINDS conducts research in its laboratories at the National Institutes of Health (NIH) in Bethesda, Maryland, and awards grants to support research at universities and other facilities. Many of the Institutes at the NIH, including the NINDS, are sponsoring research to understand what causes AS and how it can be effectively treated.

One study is using functional magnetic resonance imaging (fMRI) to show how abnormalities in particular areas of the brain cause changes in brain function that result in the symptoms of AS and other ASDs.

Another large-scale study is comparing neuropsychological and psychiatric assessments of children with possible diagnoses of AS or HFA to those of their parents and siblings to see if there are patterns of symptoms that link AS and HFA to specific neuropsychological profiles.

NINDS is also supporting a long-range international study that brings together investigators to collect and analyze DNA samples from children with AS and HFA, as well as their families, to identify associated genes and how they interact. Called the Autism Genome Project, it's a consortium of scientists from universities, academic centers, and institutions around the world that functions as a repository for genetic data so that researchers can look for the genetic "building blocks" of AS and the other ASDs.

Since there are so many different forms of ASD, understanding the genetic basis of each opens the door to opportunities for more precise diagnosis and treatment. Knowing the genetic profile of a particular disorder could mean early identification of those at risk, and early intervention when treatments and therapies are likely to be the most successful.

<sup>1</sup>Adapted from the *Diagnostic and Statistical Manual of Mental Disorders IV* and the *International Classification of Diseases - 10*

### **Where can I get more information?**

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN

P.O. Box 5801

Bethesda, MD 20824

(800) 352-9424

<http://www.ninds.nih.gov>

Information also is available from the following organizations:

**MAAP Services for Autism, Asperger Syndrome, and PDD**

P.O. Box 524  
Crown Point, IN 46308  
[info@aspergersyndrome.org](mailto:info@aspergersyndrome.org)  
<http://www.aspergersyndrome.org/>  
Tel: 219-662-1311  
Fax: 219-662-1315

**Autism Society of America**

4340 East-West Highway  
Suite 350  
Bethesda, MD 20814  
<http://www.autism-society.org>  
Tel: 301-657-0881  
800-3AUTISM (328-8476)  
Fax: 301-657-0869

**National Institute of Mental Health (NIMH)**

National Institutes of Health, DHHS  
6001 Executive Blvd. Rm. 8184,  
MSC 9663  
Bethesda, MD 20892-9663  
[nimhinfo@nih.gov](mailto:nimhinfo@nih.gov)  
<http://www.nimh.nih.gov>  
Tel: 301-443-4513/866-415-8051  
301-443-8431 (TTY)  
Fax: 301-443-4279

**Autism Network International (ANI)**

P.O. Box 35448  
Syracuse, NY 13235-5448  
[jjsincla@syr.edu](mailto:jjsincla@syr.edu)  
<http://www.ani.ac>

**Autism Research Institute (ARI)**

4182 Adams Avenue  
San Diego, CA 92116  
[director@autism.com](mailto:director@autism.com)  
<http://www.autismresearchinstitute.com>  
Tel: 866-366-3361  
Fax: 619-563-6840

**National Institute on Deafness and Other Communication Disorders Information Clearinghouse**

1 Communication Avenue  
Bethesda, MD 20892-3456  
[nidcdinfo@nidcd.nih.gov](mailto:nidcdinfo@nidcd.nih.gov)  
<http://www.nidcd.nih.gov>  
Tel: 800-241-1044 800-241-1055 (TTD/TTY)

"Asperger Syndrome Fact Sheet," NINDS. Publication date January 2005.

NIH Publication No. 05-5624

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**Join Online Social Networking Group for Case Managers on CMSNE Website**

Check out our updated webpage! We've made it easier for you to join our professional online discussion group on Linked In!

Just click on the Linked In logo and you will be directed to our CMSNE Group. If you are not yet a member, follow the online instructions for joining our group.

Even easier click on this logo and and join right from this article.



Click here to join.

Or be sure to visit our booth at our regional conference in September for 'on-the-spot' assistance with joining the CMSNE's group on Linked In.

Either way, it's an easy way to stay connected, stay on top of industry news and engage in discussions with other case management

professionals in New England. Link In-it's easy!

For additional information please feel free to contact the chapter office at [cmsne@comcast.net](mailto:cmsne@comcast.net)

## Pre-existing Condition Insurance Plan New Option Coverage for the Uninsured

If you have had a hard time finding health insurance because of a pre-existing condition or if you've been turned down for insurance coverage and feel like you're out of options, you're not out of luck. You may now be eligible for a new program created by the Affordable Care Act -- the *Pre-Existing Condition Insurance Plan*.

This transitional program is available for children and adults in all 50 states and the District of Columbia who have been locked out of the health insurance market because of a pre-existing condition. In 2014, Americans--regardless of their health status--will have access to affordable health insurance when the nation transitions to a new marketplace.

Under this new program, you'll receive health coverage for a wide range of medical benefits including physician's services, hospital care, and prescription drugs. All covered benefits are available to you--even to treat a pre-existing condition. You won't be charged a higher premium because of your medical condition and your eligibility is not based on your income. Like standard health insurance plans, you'll be required to pay a monthly premium, a deductible, and some cost-sharing expenses. Premiums may vary depending on where you live, your age, and which health plan you choose.

The Pre-Existing Condition Insurance Plan is already getting results that are changing the lives of Americans across our nation who don't have health coverage and need medical care.

James H., who lives in Texas, was diagnosed with brain cancer in 2010. . Shortly after his diagnosis, James' insurance company rescinded his insurance coverage claiming that his cancer was a pre-existing condition. James knew that his lack of coverage was a death sentence. Fortunately, James was able to join the Pre-Existing Condition Insurance Plan in Texas and is now receiving the medical treatment he needs.

Cathy A., who lives in Ohio and is a small business owner, has Systemic Lupus which has required very little treatment over the years, but she has consistently been denied health insurance because of her medical condition. Cathy noted that "without me working and paying the bills, my firm would close." After enrolling in the Pre-Existing Condition Insurance Plan in Ohio, Cathy now has the peace of mind she deserves and she doesn't have to worry about the financial instability that goes with being uninsured.

These stories are just a snapshot of what we're hearing from people across the nation who are participating in the *Pre-Existing Condition Insurance Plan*.

To qualify, you must: be a citizen of the United States or residing here legally, have been uninsured for at least 6 months before applying, and have a pre-existing condition or have been denied insurance coverage because of your health condition.

Each state may use different methods to determine whether you have a pre-existing condition and whether you have been denied health coverage. To find out more about the Pre-Existing Condition Insurance Plan, including eligibility, plan benefits and rates and how to apply, visit [www.pcip.gov](http://www.pcip.gov) or Click on "Find Your State" and select your state from a map of the United States or from a drop-down menu for details.

You can also dial the Call Center toll free at **1-866-717-5826 (TTY 1-866-561-1604)**. The Call Center is open 8 A.M. to 11 P.M. Eastern Time.

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