

## The AUsome Social Group

Teen/Young Adult Recreation/Social Group

Sponsored by the Autism Society of Greater Madison (ASGM)

Contact: Nancy Alar, 3802 Gala Way, Cottage Grove, WI 53527

(608) 222-4378 or [ausome@hughes.net](mailto:ausome@hughes.net)

- What:** Medical Home Community Conversation/Resource Sharing (Starting with a Pizza Lunch – Gluten free pizza and snacks will be available)
- When:** March 6th, 2010 (Saturday), Noon - 2:00 p.m.
- Where:** Waisman Center, 1500 Highland Ave., Conference Room Ziemann A, on the 8th floor
- Cost:** Free! Bring Information about Any Medical/Community Service that Has Worked for You

This is your chance to make your voice heard in the Autism Community. The Southern Regional Center for Children and Youth with Special Health Care Needs would like to hear from individuals on the autism spectrum (and their families) about the community resources you value in the areas of:

- Health care and going to your doctor
- Mental health and feeling good about yourself
- Dental care
- Therapies, interventions, or medications
- Living in the community

The ultimate goal of this meeting is to add to the resource list that is being compiled by the Southern Regional Center for Children and Youth with Special Health Care Needs that is based in the Waisman Center. This Southern Regional Center is part of the effort to promote the development of the concept of “Medical Home”. The focus of the Medical Home is to provide better coordination and access to various medical related services/resources in all aspects of the lives of those on the spectrum. Many people in the autism community all over Wisconsin are involved in this effort. A special thanks to Gail Chodron and Kristin Gowan for setting up this activity and providing the pizza and other refreshments.

### Schedule

- 12:00 Settle in and get pizza, snacks and softdrinks!
- 12:15 Review of resources that are available—an introduction from Kristin Gowan
- 12:30 Community Conversation about Resources  
What resources that helped you would you want others to know about?
- Health care and going to your doctor
  - Mental health and feeling good about yourself
  - Therapy, interventions, or medications
  - Dental care
  - Living in the community
- List one resource you have needed that you haven’t been able to find.
- 1:45 Share additional novel resources. Research study opportunities, dental school contacts, volunteer mental health resources. Drug companies paying for meds you can’t afford. All attendees will get Transition Guides published by DPI.
- 2:00 Thanks!!

- ☺ Parking in the back of the Waisman Center is free on Saturday
- ☺ Look for signs on the doors for the entrance to use
- ☺ We will have gluten free pizza and GF/CF snacks available

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- What:** James Williams, a nationally known Young Man with Autism, will Discuss and Explain the “Hidden Curriculum” of Facebook.
- When:** Friday Evening, April 2, 2010; 7:00 – 8:45 P.M.
- Where:** Sequoya Library , 4340 Tokay Blvd. Madison - Corner of Tokay Blvd. & Midvale Blvd. (Across the Street from the Church), Meeting Room B
- Cost:** Free! Bring a snack to share with James and your AUsome friends

The Midvale Lutheran Church is still under construction, so we will meet at the library across the street.

Some of you may have met James Williams at our September, 2007 and April 2008 AUsome activities where he spoke to us about “Understanding the Hidden Social Curriculum” and led us in an AUsome version of “Are You Smarter Than a 5<sup>th</sup> Grader?” James also will do/did the same Facebook presentation he’s doing for us at our ASW State Autism Conference in Green Bay on March 20. I first saw James speak at a conference in Indiana when he was only 12 years old. James lives in Northbrook, Illinois, a Chicago suburb. He is now twenty years old and has high-functioning autism. He uses buses and trains to travel around the country by himself.

James has spoken at several autism conferences, parent support groups, and special schools. He has had several correspondences with individuals (normal and autistic) who are interested in his advice. He is also the co-author of [The Self-Help Guide For Special Kids and Their Parents](#) and the author of [Out To Get Jack](#). On his website, he has archived his speeches and essays he has written over the years. You can see a picture of James and read his materials at <http://www.jamesmw.com/#1>

Facebook is a very popular internet social networking site for many individuals around the world. Facebook has become not only popular with adolescents, but with adults as well. Some people with autism also enjoy using Facebook as there are ample abilities to chat and instant message their friends, and some autistic people prefer online communication rather than face-to-face or telephone conversation because of speech, eye contact, and other personal communication related difficulties.

However, in order to properly use Facebook, there is a social code and rules that users are expected to follow. Like any other part of society, Facebook has a hidden curriculum of its own that not all people with autism might necessarily understand.

In this presentation, James will discuss my experiences on Facebook, and the social code that he learned and was taught by other Facebook users, as well as mistakes he made along the way. James will also discuss features that Facebook offers, as well as issues regarding privacy and safety. He will explain how Facebook was created to actually guarantee a higher level of privacy and safety than other social networking websites. There will also be time for individuals with autism and their parents and friends to ask James questions about Facebook.

We’ll share our snacks while we listen to James teach us about the Hidden Curriculum of Facebook.

### **Important Items and Sensory Issues:**

- ☺ Bring a snack food to share; I will provide drinks and plates, etc.

### **Important Information:**

1. Visit <http://www.autismmadison.org/> for other services and activities sponsored by the **Autism Society of Great Madison (ASGM)**. The 3<sup>rd</sup> Tuesday evening of the month is either a parent support group meeting at the Midvale Community Lutheran Church or a special presentation. There is also sensory friendly Saturday movies on the last Saturday of the month and quarterly birthday parties at “Pump-it-up”. There are also many other special events (such as A-Maze-ing Days at the Treinen Farm Corn Maze) through out the year.
2. **The Annual Autism Society of Wisconsin (ASW) conference will be March 18-20, 2010 at the Hotel Sierra (formerly the Regency Suites) in Green Bay.** This is much earlier than usual. The registration form is a little confusing because the full conference rate for someone on the spectrum is \$90 (up from \$60 last year, but still a real bargain) regardless of when you register. Parents and other attendees have to pay a lot more. See the ASW web site for more information - <http://www.asw4autism.org/>.

Yes! We will have 2 special autism conference strands (youth and “across the lifespan”). We will have a hospitality room and an art/favorite things display. On Friday evening, we’ll have a pizza supper, a talent show, and a dance. Register early so we know how many to plan for.

At this conference we try to make those on the spectrum as comfortable as we can. We will take sensory issues and dietary restrictions into consideration as much as possible. Those who want to participate in the youth and self-advocacy strands will need to register for the conference and pay the registration fee (the fee for those on the spectrum is only \$90!). This conference is a place where those on the spectrum are valued for their differences. You are the reason this conference exists.

## What Happened at AUSome's Last Outings?

### 47<sup>th</sup> Annual Madfest Juggling Show at Wisconsin Union Theater; January 16, 2010 (Saturday) 7:00-9:30 P.M.

For the first time in my memory, we didn't have below zero wind chills for the juggling show night! It (almost) seemed like spring!

You never know what you will see at this event. It isn't so much a juggling show as an object manipulation show. Everyone who attends says it's almost impossible to describe to someone who hasn't seen it. For example: One memorable happening was an appearance of a group of young folks who juggled while riding 2(?) wheeled skate boards. One of the AUSome members informed me these are called "Rip Sticks". I couldn't believe anyone could ride these things let alone juggling while doing it. --- you just had to be there. We had about 100 AUSome folks signed up to come this year. A big thanks to my daughter Liz and her posse (Kate, Laura, Emily, Josh and Stacy) and to Sarah Kover for helping me organize things and pass out the tickets!

Another big THANKS to Mark Hayward and Katherine Gir daukas for helping me set this up and to the Capital Time's Kid's Fund for paying for the tickets. As usual, some people were making balloon animals, juggling and doing magic tricks in the audience both before the show and during the intermission. We also had fun with the balloons that came down from the balcony during intermission.

Mark Hayward started off with his own version of the William Tell "shooting the apple off his head" trick. "Big Mark" introduced "Little Mark" which may have been his son, but I'm not sure. But I am sure that Mark convinced cheeky "Little Mark" to balance a poker chip on his ear and then "Big Mark" knocked the poker chip off Little Mark's ear with a very dangerous looking yo-yo. At the time, Big Mark's yo-yo was doing a series of very fast "around the world" moves. Big Mark could have done a lot of damage if he had missed the poker chip and hit Little Mark in the head. But Little Mark didn't seem at all scared or concerned. He traded wise cracks with Big Mark all through the act.

Dizzy Lizzy Delicious did a really cool act with hula hoops. I think at one time she had about 10 hula hoops flipping around her body. Charlie Keys was a cowboy who did an act with one of those western cowboy whips where he knocked flowers off from a distance. He also juggled (sort of) a pair of six-shooters in his holsters. He was a juggling quick-draw artist.

Mobile ZOC was the group with the 2-wheeled skate boards. These boards were about the same length as a regular skate board, but they were jointed in the middle and had one wheel under each end. They looked totally dangerous to me. Thom Wall did his "Zone of Catchability" act with a bunch of green balls.

Steven Ragatz did this incredibly funny pantomime act that was supposed to illustrate how hard it is for someone to get up in the morning after a long day of juggling. He pretended to keep falling asleep while he was doing such things as taking a shower, shaving and dressing. It was amazing how he could get you to understand exactly what was happening even though it was just him on stage without even any props. At the end of this act, Steve got dressed in a grey suit and left the stage with a cane and brief case like he was going to work. Later he came back out on the stage with the cane and brief case and pretended he was waiting for a bus next to what looked like a street light with 5 red globes. The red globes turned out to be juggling balls which he plucked off several at a time and proceeded to juggle them on the brief case and the cane (along with his hat). He rolled the balls along the sides of the briefcase and up and around the cane. It was very creative. I think they said he has performed with Cirque du Soleil.

Doug Sayers was a world champion ring juggler. Amanda Crocket did an almost indescribable routine where it looked like her arms and legs had a mind of their own and she was having trouble controlling them. It was all very funny. She followed that with a hat juggling routine. The 3 person Smirk troupe was the final act. It was all very entertaining.

## **Native American (American Indian) Storytelling; January 29, 2010 (Friday), 7:00 – 9:00pm**

To make up for the fact that it wasn't too cold for the Juggling show, it was freezing cold for this activity in the same location as the juggling show. We only had 8 AU some people show up, but the auditorium was full anyway. A big thanks to Stephanie Dodge of the UW Indian Studies Dept. for helping me make the arrangements for our group to attend. This was the 13<sup>th</sup> annual Indian Story Telling Event.

The show started out with a 15 minute Native American drumming performance. I was concerned that the drumming would be loud and a problem for those who were noise sensitive, but it was actually soothing. Eight different guys played one big drum all at the same time. The drumming wasn't real loud and it was accompanied by very soothing chanting and rhythmic beats. The purpose of the drumming was to honor the story tellers.

After the drumming, there was an introductory presentation where they explained that traditionally stories were told in the winter because there wasn't much else to do then. They had planned to have 4 different American Indian Elders from the United States and Canada doing American Indian Storytelling in their native language. But Sequoyah Guess wasn't able to make it. The 3 story tellers we did hear were:

- Joey Awonohopay, Menominee language
- [Nancy Jones](#), Ojibwe language
- [Mary Louise Defender Wilson](#), Dakota-Hidatsa language

Joey Awonohopay comes from a long line of story tellers. His last name means "He who sits in the Mist". His childhood home was in a very remote area, so he was able to learn stories from his father and grandfather without the distractions of the white man's civilization. Joey told us several stories and then translated what they meant at the end of each one. The first story was how the chipmunk got its stripes. The basic plot was that the chipmunk was really annoying and teased the other animals with its shrill chirping. Finally the bear got so fed up with all the teasing that it scratched the chipmunk on its back – causing the stripes. The moral of the story is you will get in trouble if you tease others and are annoying. The word for chipmunk in the Menominee language sounded like "cocky cosac". Joey made the chirpy chipmunk noises as he was telling the story. By the end of this story, I could pick out the word for chipmunk whenever he said it. Joey also told stories about how the Great Spirit created the sugar maple tree and how the mountain lion got a flat face (a deer tricked him into running into a tree).

Nancy Jones

## **AUSome Social Group Philosophy and Ground Rules**

### Group Sponsor:

The AUSome Social Group is sponsored by the Autism Society of Greater Madison (ASGM). **It is highly recommended that you join the Autism Society of Greater Madison. You should at least subscribe to the Autism Society of Greater Madison newsletter (subscription cost is only \$5) if you are not a chapter member.** It is possible that Madison chapter membership may be required in the future as the AUSome group becomes larger and requires more resources. You can get more information about the Madison Chapter (including an extensive autism resource list), by calling (608) 213-8519 or sending a note to ASGM, 2935 Fish Hatchery Rd #101, Madison, WI 53711

See the ASGM website at <http://www.autismmadison.org/> for membership information and a link to the AUSome Group web pages <http://www.autismmadison.org/ausome/index.htm> . If you join the Autism Society of Greater Madison, this automatically gives you the chapter newsletter plus membership in both the state (ASW) and national Autistic Societies so you will get all those mailings as well. (Changes are underway with national vs local membership, so check with the website to confirm membership details.)

### Group Purpose:

The AUSome group was organized to provide recreation and social opportunities for people ages 12 and over who are challenged by sensory/communication issues related to Autism/Asperger's/PDD/Tourette's. However, anyone is welcome to join the activities. I try to set up activities that allow for social interaction between group members and between parents and siblings of the group. Friends of group members are welcome to come along.

### The AUSome Newsletter:

The AUSome Group has a separate newsletter that is sent out every other month, containing details for the next 2 outings and a summary of what happened the past 2 months. The AUSome newsletter will be sent out at least a week in advance of the next outing (I hope). Some things may be planned with short notice if something interesting comes up. If you have an e-mail address and are OK with receiving the newsletter that way, let me (Nancy Alar) know. It saves time and postage if notification can just be sent electronically. I will maintain a mailing list of participants, and will verify this list annually – usually in January in conjunction with a call about tickets to the juggling show. Our AUSome newsletter is also available on the web at <http://www.autismmadison.org/newsletter/index.htm>

### General Activity Plans:

The general plan is to have an activity about once a month that will last from 2 to 4 hours. The target day will be the first Saturday of the month. However, this is subject to schedule conflicts and availability of interesting activities. Activities that we have done include bowling, miniature golf, gymnastics, movies, a talent show, art gallery visit, fossil hunt, Little Amerricka (a local amusement park), swimming, horse back riding, Go Cart driving, farm market, airplane rides, pottery making and a limousine ride. Each January we attend the 47<sup>th</sup> annual Madfest Juggling show. In August we join other ASGM members for a private pool party at the Monona Pool. Every November we have “video game night”. If you are especially interested in a particular activity or have other suggestions, please let me know.

### Sensory Issues:

Every effort will be made to accommodate sensory issues by limiting cigarette smoke, strong odors, unusual lighting, large crowds and high noise levels where possible. If an activity might involve some of the sensory problems mentioned above, they will be described in the AUSome newsletter. It will not be possible to accommodate everyone's needs all the time so individuals must decide their tolerance levels for each activity. Please let me know if you have any special requests in this area. Also, please be sensitive to requests from group members who have special sensory needs (such as problems with others chewing gum.).

### Logistics:

Some individuals may need to arrange for a support person to accompany them. Please use your best judgment in this area. Transportation will be the responsibility of each individual. However, effort will be made to provide help with transportation by designating central meeting points, etc. **Please call me, Nancy Alar, (608) 222-4378 or e-mail me at [ausome@hughes.net](mailto:ausome@hughes.net) if you have transportation problems, and I'll try to help work out a way for you to get there.**

Since these activities are loosely organized social outings, each person participates at their own risk.