2014 MOFAS conference

FASD matters.

FASD and human rights

November 13-14, 2014
Minneapolis Marriott NW, Brooklyn Park, Minnesota

mofas.org
The Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) is the statewide organization serving as the leading voice and resource on Fetal Alcohol Spectrum Disorders (FASD) in Minnesota – standing up for the rights of the FASD community. MOFAS understands that the challenges families living with an FASD face are intense and at times, may even be overwhelming. There is a need to address this lifelong disability medically and socially in order to protect the rights of individuals, families, and community impacted by FASD. It is imperative that the civil rights and human rights of all individuals with an FASD be acknowledged, protected, and enforced. Join us on November 13-14 and immerse yourself in learning, problem solving, and discussing how we can improve equal access and human rights for the FASD community.

Who Should Attend

The conference is open to family members, caregivers, service providers in health/mental health, addictions, justice, education, adoption, prevention, child welfare and anyone interested in Fetal Alcohol Spectrum Disorders.

Conference at a Glance

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<th>Thursday, November 13, 2014</th>
<th>5:00 PM – 7:00 PM</th>
<th>Welcome Reception and MOFAS Annual Celebration featuring special guest Billy McLaughlin</th>
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<td>Friday, November 14, 2014</td>
<td>7:00 AM</td>
<td>Registration, Continental Breakfast, Exhibits and Networking</td>
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<td>7:20 AM – 8:20 AM</td>
<td>Breakfast/Networking/Early Bird Breakout Session</td>
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<td>8:30 AM – 9:30 AM</td>
<td>Welcome and Keynote Address: Jonathan Mooney Neurodiversity as the Next Civil Rights Movement</td>
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<td>9:30 AM – 9:45 AM</td>
<td>Break: Exhibits and Networking</td>
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<td>10:45 AM – 11:00 AM</td>
<td>Break: Exhibits and Networking</td>
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<td>Noon – 1:45 PM</td>
<td>Lunch and Keynote Address: Jacob’s Story</td>
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conference planning committee

Sierra Beckman
Minnesota Department of Health, Children and Youth with Special Needs

Bruce Beneke
Southern Minnesota Regional Legal Services

Cathy Bruer-Thompson
Retired Hennepin County Adoption, MOFAS Board Member

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Jennifer Moore
Moore Family Law, Conference Sponsor

Wendylee Raun
MN Adopt, Former MOFAS Board Member

Ruth Richardson
FASD matters Conference Chair, MOFAS

Jeff Wozniak
University of MN, FASD Clinic
welcome reception and MOFAS annual celebration

Thursday, November 13, 2014, 5 PM-7 PM
Minneapolis Marriott NW, Brooklyn Park, MN

As a kickoff to this year’s FASD matters conference, you are invited to a welcome reception and Annual Celebration where you can network with other conference participants and enjoy an inspirational message from special guest and Minnesota native, Billy McLaughlin.

Life After Diagnosis

For 20 years, Billy astounded audiences around the world with his complex and rhythmic music. He was recognized internationally as a world-class guitarist, composer, and inspirational performer. His decades of national concert touring earned him a spot on Billboard’s Top Ten Chart, 5 Minnesota Music Awards, and a Hall of Fame Achievement Award.

But then in 2001, Billy was diagnosed with a little-known, neuromuscular disorder that rendered him unable to play his music. When diagnosed, he was actually relieved to know what was wrong with him. And despite the fact the prognosis for his musical career was grim, his mantra became “accept the diagnosis, reject the verdict”.

For anyone who has been affected by sudden, future-changing events, Billy’s honest and deeply personal story on diagnosis to self-discovery, with just the right amount of music mixed in, will truly be an unforgettable experience.

We hope you will join us for this special evening to connect, learn, and celebrate. This event is FREE and open to all, but registration is required. Go to http://bit.ly/2014fasdmattersregistration.

This event is generously sponsored in part by the Schillo Family and Lundbeck LLC.

CEUs

Earn up to 7 Continuing Education Credits

The conference is designed to meet the Continuing Education Hours credits for many disciplines: psychology, social work, education, nursing, marriage and family therapy, behavioral health, licensed alcohol and drug counselors, and attorneys. Certificates of attendance will be available to conference participants.

MOFAS has applied to the following for Continuing Education Credits: Minnesota Board of Continuing Legal Education; Minnesota Board of Social Work; the Minnesota Board of Psychology, the Minnesota POST Board, NAADAC – National Association for Addiction Professionals, and Professional Education Pal.
Jonathan Mooney
Neurodiversity as the Next Civil Rights Movement

developing organizations, programs, and initiatives to improve the lives of marginalized groups. As the founding president and Executive Director of Project Eye-To-Eye, Jonathan grew the organization from an undergraduate project conceived in his dorm room into a national organization, which currently has 38 chapters in 20 states working with over 10,000 parents, educators, and students.

Jonathan has published two books, Learning Outside The Lines and The Short Bus: A Journey Beyond Normal, and has established himself as one of the foremost leaders in the neurodiversity and learning revolution. He is a highly sought after speaker on neurodiversity, education reform, the learning revolution, and creating college and career pathways for at risk youth, and has lectured in 43 states and three countries.

Jacob’s Story

Jacob’s Story is a unique and moving theatrical performance to increase understanding of Fetal Alcohol Spectrum Disorders (FASD) from the perspective of an individual with an FASD.

The play follows the life of Jacob, a little boy with an FASD and his family. Throughout the story, the audience will ride the emotional “roller coaster” of dealing with school systems who don’t understand the nature of FASD as a physical disability, the struggles of caregivers to get the help their child needs, and how the Criminal Justice System is unprepared to deal with this disorder as it conflicts with the rules of society.

Whether you are a health, social service, justice or education professional, Jacob’s Story will provide a deeper understanding of the whole picture, and the extent of the heartache FASD can create in the lives of the children and their families, and how important it is for those in the life of someone with an FASD to understand this invisible disability.

Cast from Left to Right: Sue Kobus, Emma McNichols, Sam McNichols, Daniel Pauley, Cathy Griffin, Len Whalen, Susie Jenkins, Susan Hazel

This production is generously sponsored in part by NeuroDevNet.
This bonus programming is offered complimentary to registrants of the 2014 FASD matters conference. Separate registration is required for these bonus webinars.

**FASD Basics**

**On-Demand Pre-Conference Webinar**

Interested in a free primer on the FASD Basics ahead of the 2014 FASD matters conference?

All conference attendees may access a complimentary bonus recording of the previously recorded FASD Basics presented by Dr. Jeffrey Wozniak of the University of Minnesota. The FASD Basics recording will be posted online between November 1, 2014 through November 14, 2014 and may be accessed at http://www.mofas.org/fasdmatters. Certificates of attendance and CE is not available for viewing the pre-recorded webinar.

CME, Nursing, Social Work, Psychology, or Addictions credits are available for the live session of the FASD Basics on October 29, 2014 presented by Dr. Wozniak from 1:30 pm – 3:00 PM (CST). Cost is $25 and registration is open at: http://bit.ly/OctFASDbasics.

**An Introduction to Human Rights**

**Pre-Conference Live Webinar**

Presenter: Ruth Richardson, JD  
November 5, 2014  
Noon – 1:00 PM (CST)  
Free

A human-rights based approach and framework should serve as a foundation to address Fetal Alcohol Spectrum Disorders to protect and promote the rights of children, women, families, and communities impacted by this disorder. This presentation will provide an introduction to human rights, its intersection with FASD, and an overview of the draft MOFAS Recommendation on a Human Rights Response to FASD.  
Register at http://bit.ly/2014humanrights. This live webinar is limited to the first 100 conference registrants. A recording of the webinar will be posted online at http://www.mofas.org/fasdmatters.

**Create Calm: Without the Storm!**

**Post-Conference Live Webinar**

Presenter: Samantha Moe, M.A., SLP  
November 20, 2014  
Noon – 1:30 PM (CST)  
Free

Are you frustrated with your child’s poor listening, defiance and lack of self-control? Discover the number one reason for intense behavior and what you may be doing that unintentionally fuels the fire. In this interactive presentation you will receive the top 3 holistic strategies from the innovative 5 Polka Dot PotionTM to calm behaviors associated with ADHD, Autism, and FASD. You will learn the:

- Number one reason for intense behavior and how to create calm
- Best method to eliminate power struggles and improve cooperation
- Easiest ways to transform negative attitudes into joyful connection and mutual respect

Register at http://bit.ly/2014createcalm. This live webinar is limited to the first 100 conference registrants. A recording of the webinar will be posted online at http://www.mofas.org/fasdmatters.
a1. Experiential Therapies to Reach Individuals with an FASD  
JoEllyn Steele, MA  
This presentation will explore the importance of access to appropriate services for individuals on the spectrum. An overview of how therapies such as Equine Assisted Psychotherapy and Sand Tray therapy have led to better outcomes, more engaged clients, and better understanding for families than through traditional talk therapy.

Liam Curran, MSc  
Children are dependent on adults for their well-being and happiness. The decisions that adults make dramatically shape a child's life. It is well established in international research, that a disproportionate number of children born with prenatal alcohol exposure enter child protective and/or state foster care services. This presentation will highlight the crucial skills needed in both the pre- and post-diagnostic challenges of placement and support to ensure the best outcome for the child.

c1. It's a Matter of Justice: Modifications for Disability in the Court Room  
Hon. Bruce Peterson, Hon. Michael Jeffery, & Susan Shepard Carlson, JD  
FASD, trauma, and mental health disorders can affect those appearing in court. How judges adapt in these situations is a work in progress. This session will explore strategies for modifying the courtroom to provide mental health-, trauma-, and FASD-informed approaches.

d1. From Deinstitutionalization to Mass Incarceration: The Human Rights Tragedy of FASD  
Susan Rich, MD, MPH  
This presentation will explore the role of deinstitutionalization and lack of community programming as contributors to mass incarceration of individuals with this misunderstood disorder. It will also highlight methods successful treating post-institutionalized children with an FASD from Russia and Eastern Europe.

e1. ACES: The Study, the Data, and the Human Rights Informed Minnesota Response  
Autumn Baum, JD & Mikki Maruska, MA  
An extensive growing body of research documents that adverse child experiences are linked to poor physical, mental health, chronic disease, lower educational and economic achievement, and impaired social success. This session will explore how adversity impacts the developing brain and what are the factors that buffer the impacts of early adversity.

a2. Navigating Life with an FASD: The Right to a Good Life  
Kathy Hotelling, PhD, ABPP  
Individuals with an FASD have a right to a “good life.” This presentation will focus on how a vision for a good and productive life that meets the needs of the individuals can be achieved through the combined efforts of caregivers, professionals, and individuals on the spectrum.

b2. The Right to an Education: Supporting School Success for the Exceptional Learner  
Deena McMahon, MSW, LICSW  
Education is a fundamental human right and essential for the exercise of all other human rights. This session will focus on specific adaptions that can provide necessary supports and accommodations that students with an FASD often need at school. An example of an IEP will be offered as well as practical suggestions to promote a more positive experience for the child, teacher, and parent.

Cynthia Moore & Jennifer Moore, Esq.  
Adults with a disability have the right to live independently and be included in the community. This session will explore the human rights issues and tensions that may arise in parenting adult children with an FASD. The presentation will also discuss ways that social services and legal systems have worked to preserve or impede the human rights of our children on the spectrum.

d2. Barriers to Justice: From False Confessions to Mental Health and Ineffective Assistance of Counsel  
Edward Cassidy, Esq. & Steven Kaplan, Esq.  
This session will explore the barriers to justice that may be faced when working with vulnerable clients and those on the spectrum. These barriers can stand in the way of ensuring the human rights of the accused. This session will highlight the barriers and strategies for addressing.

e2. Young Adults Involvement in the FASD Movement  
Marissa Lang, BA & MOFAS Young Adult Panel  
Young adults on the spectrum have the right to meaningful involvement in the FASD movement to improve youth transition outcomes. This session will provide a forum for young adults to explore a variety of human rights themes related to education, employment, and other transition issues. Time will also be reserved to share an exciting update for developing youth with an FASD as national leaders as a result of a collaboration between MOFAS and the National Collaborative on Workforce and Disability.
Additional content has been removed to focus on the given text.

**7:20 AM - 8:20 AM session a**

**a3. Annual FASD Research Update**
Jeff Wozniak, PhD

Want to find out more about what is going on in the FASD Research field? Join us for an exciting annual FASD Research Update. In Minnesota, we are fortunate to have one of the national leaders on FASD and research available to provide an up to the minute research update for consumers and professionals.

**a4. The Greatest Human Rights Challenge of our Time: Trafficking and Sexual Exploitation**
Sgt. Grant Snyder

Kids with abuse and trauma in their past, autism, and/or Fetal Alcohol Spectrum Disorders are particularly vulnerable to sexual exploitation. Explore issues related to vulnerability, challenges to ending sex trafficking, and the story of Saving Bobbi, a young woman on the spectrum who was the victim of sex traffickers and her story of hope.

**9:45 AM - 10:45 AM session b**

**b3. Criminalization of Mothers Struggling with Addiction**
Tom Castelli, JD

A recent law passed in Tennessee singles out new mothers struggling with substance abuse for criminal assault charges. The law raises constitutional concerns regarding equal treatment under the law and jeopardizes families by deterring women who need help from seeking prenatal care. This session will explore the constitutional implications of the law and provide alternatives to the criminalization of mothers struggling with addiction.

**b4. A Call for Action: The FASD Caregiver Bill of Rights**
Michael Harris, MA, LP, SEP

Caregivers of those on the spectrum understand the incredible time, energy, emotion, and stamina needed to properly parent those with an FASD and still maintain a healthy life balance. Sixteen states have adopted a foster care bill of rights. It is time for caregivers to begin the development of an FASD Caregiver Bill of Rights. This session will highlight the diverse voices of caregivers for a stronger FASD parenting foundation.

**11:00 AM - Noon session c**

**c3. From Stigma and Discrimination to a Circle of Hope: Birth Mothers Reflections on Human Rights**
Michele Fournier, LADC & MOFAS Birth Mother Panel

The FASD research community now understands FASD as a complex societal problem. Birth families often face stigma, isolation, and judgment preventing them from accessing necessary supports. This session will give a voice and face to a courageous group of women that are committed to moving from stigma to a circle of hope for families impacted by FASD.

**c4. Making Employment Work for You**
Dan Stewart, MA, JD, PhD

The Universal Declaration of Human Rights states everyone has the right to work. This presentation will include obtaining integrated, competitive employment and more: SSDI/SSI basic information, Work Incentives, PASS Program, Ticket to Work Program, School-based transition, special education services, MA for Employees with Disabilities, Substantial Gainful Activity, Wage Reporting, and Resources for Benefits Planning.

**1:45 PM - 2:45 PM session d**

**d3. Applying a Human Rights Standard to Restraint and Seclusion in Minnesota Schools**
Charles Young & Dan Stewart, MA, JD, PhD

Seclusion and restraint in schools raise human rights issues. This panel presentation will provide a background on general statistics, legislative changes in Minnesota, initiatives to prevent use, medical perspectives on use, effects of restraint and seclusion, and changes to Minnesota's Home and Community Based Services Standards (Minn. Stat. 245D).

**d4. A Gateway to Services for Families: The Importance of Access to Medical Assistance**
Jen Daulman Johnson, BA, & Ryan Anderson Pascual, BA

Effective services and supports are essential for the success for those with an FASD. Families may find the application process complicated or overwhelming. Also, families may encounter barriers. The Affordable Care Act has resulted in many changes to the health care system. The session will provide information about MA, TEFRA, SMRT, MA-EPD and other publicly funded options.

**3:15 PM - 4:15 PM session e**

**e3. Medical Evaluation for FASD: More than Size, Lips, and Eyes for Optimal Health**
Judith Eckerle, MD

Medical patients have a right to adequate and appropriate care. This session will highlight the medical evaluation for a child with possible prenatal alcohol exposure. This session will explore how a comprehensive medical evaluation is key to ensuring the optimal health in a child with suspected prenatal alcohol exposure.

**e4. Know Your Rights: From Social Security to Guardianship**
Amy Dawson, Esq. & Jason Schellack, Esq. & Mikel Sporer, Esq.

This fast-paced seminar will offer tips on applying for social security and guardianship. Topics include: defining SSDI and SSI, the definition of disability, charging rent as a strategy, qualifying for free assistance when establishing guardianship, and much more.
More Information at:
http://www.mofas.org/fasdmatters

Registration
Registration will be accepted through November 7, 2014 and includes admission to all sessions, program materials, refreshment breaks, continental breakfast and lunch, and a certificate of attendance. On-site registration will be allowed as space allows. To register go to http://www.mofas.org/fasdmatters

Confirmation
Prior to the conference, participants will receive an email confirming their registration. This email will also contain a password to access conference handouts online. Handouts will be available through December 31, 2014.

Cancellation Policy
Paid registrants that cancel their registration prior to October 15, 2014 will receive a full refund. Paid registrants that cancel between October 15, 2014 and November 3, 2014 will receive a credit minus a $25 administrative fee that will be deducted. No cancellation refunds will be processed after November 3, 2014.

Scholarships
If registration fees are a barrier to your participation, a limited number of partial scholarships are available for attendees that live in Minnesota. Please contact Ruth Richardson at ruth@mofas.org or call MOFAS at 651-917-2370 for more information.

Location
The conference will be held at the Minneapolis Marriott NW, 7025 Northland Dr. N., Brooklyn Park, Minnesota and is located just north of 694 and west of Boone Ave.

Hotel Accommodations
A special conference room rate of $129 + tax has been secured at the Minneapolis Marriot NW for conference participants. Please make reservations directly with the hotel by calling 1-877-303-1681 by October 22, 2014 and ask for the FASD Conference rate. You can also book online by going to http://bit.ly/2014conferencehotelroom.

New “Family Room” Option
To accommodate consumers at this year’s conference we are offering a family room option. This space will provide an opportunity to connect with other families and network. Some of our guest speakers may also make appearances throughout the day.

Workshop Selections
All sessions are filled on a first-come basis. Some sessions may reach capacity. If you see a sign on the door indicating the session is full, please select another session.

Accessibility
The Minneapolis Marriott NW is compliant with the Americans with Disabilities Act. If you need an accommodation (e.g., wheelchair accessibility, Sign Language Interpreter), such accommodations will be made available upon advance request. Please contact Ruth Richardson on or before October 1, 2014. For TTY, contact Minnesota Relay Service at 1-800-627-3529.
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<th>Name</th>
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<tr>
<td>Ryan Anderson Pascual, BA</td>
<td>ARC Greater Twin Cities</td>
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<td>Autumn Baum, JD</td>
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