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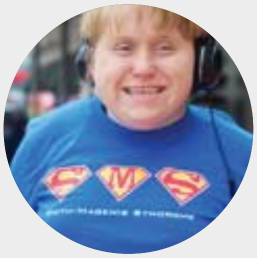
PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

INSIDE THIS ISSUE



PRESIDENT'S MESSAGE

GOOD WISHES TO ALL, AND WELCOME TO OUR MID-2017 NEWSLETTER.

We are in the midst of a non-conference year. This is a quiet time when much effort is devoted to preparing for our next international conference. In 2018, we will gather in Pittsburgh from July 19-21 for our 10th international conference. I sincerely hope you will join us and help PRISMS celebrate its 25th year serving all of you in the Smith-Magenis community.

HONORING THE PAST / TREASURING THE PRESENT / SHAPING THE FUTURE

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10TH INTERNATIONAL

CONFERENCE

PITTSBURGH 2018

As many of you know, the conference is our major program offering. It is a chance to connect with others, to learn from families and expert presenters and to re-affirm and strengthen your sense of direction and purpose for your family member.

Also during this non-conference year we have a chance to review, build and strengthen other parts of the organization. Here are a few highlights:

We have conducted an audit of our communication methods—the way we use social media and other publications to serve you. In our changing world, it is hard for a small organization to keep up with every technical advance. This professional audit has helped us understand how to build upon what works and to improve other areas.

Based on a targeted survey and from a thorough analysis, we learned the website is the most important resource for our community. As a result, we have launched a major initiative to update the content and how it is organized.

Together, these two efforts will yield more up-to-date information, a more clearer presentation and a more supportive and engaging resource for you. There is an army of volunteers, consultants and staff working together on this project. Even after we launch the new website, we will be open to hearing from you and making it even better.

On May 18 and 19, our Professional Advisory Board (PAB) convened our 9th Research Symposium at Baylor College of Medicine in Houston. The two-day gathering included a face-to-face meeting by the PAB and a day of presentations by a variety of experts. Soon, we will share a report that outlines the state of research into Smith-Magenis Syndrome and priority areas to focus our support.

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Parents and Researchers Interested
in Smith-Magenis Syndrome

Research Symposium

Finally, there are many people working behind the scenes to strengthen PRISMS and make it the best organization it can be. In our work plan are strategies to build our regional representative program, for the board to update the strategic plan and to prepare a worthy celebration of 25 years of service.

I am excited to be part of these efforts. Working together, I know we can do much to make a positive difference for you and others in our community.

Best wishes to you all!

John Mayer
President, Board of Directors

Together We Are Stronger

Volunteers and Fundraisers Needed

By Emily Fields

PRISMS is a 501c3 nonprofit organization committed to serving the SMS community through programs and services dedicated to education, awareness, and research. We are looking for support from YOU to help ensure we can continue to grow and improve our services for your families and the professionals who serve you.

We ask that you get involved today:

1) Make a Donation

Your contribution is more than a donation, it is how we will impact the lives of thousands effected by SMS, the families who love them, and the professionals who serve them. http://www.prisms.org/how-to-help/make-a-donation

2) Start an Event

To date, our community members have raised more than $50,000 for SMS through fundraisers and events in their local areas. You too can make a difference! Others in the SMS community have hosted vineyard walks, happy hours, concerts, art auctions, car shows, movie nights, picnics and much more—all to help support PRISMS. And it ALL matters. Let your talents and interests lead you to your own fundraising endeavor. The ideas are endless. And we're here to help. Not sure where to start? Contact me today, efields@prisms.org.

DID YOU KNOW? You can EARN FREE CONFERENCE FEES AND HOTEL NIGHTS for PRISMS 10th International SMS Conference just by organizing small fundraising events! http://www.prisms.org/whats-new/earn-free-conference-fees

We want to help you get to Pittsburgh and join us for the conference! Reach out at info@prisms.org to get started earning those freebies.

3) Become a Volunteer

We accept volunteers from around the world. You can help PRISMS make an impact by giving of your time and talents in service as a volunteer. There are a variety of ways to volunteer including as a committee member, specific project-by-project basis, as a board member and more!

On the next page you'll find a list of active volunteer opportunities. Interested in learning more about one of these opportunities or in volunteering with PRISMS in a different way? Contact us today at info@prisms.org

Together We Are Stronger

Volunteers and Fundraisers Needed

AWARENESS

Social Media: Develop social media posts and asks based on monthly themes—(2-4 people)

Blog: Develop monthly personal blog posts—(4-6 people)

FUNDRAISING

Assist in creation of fundraising events, raising excitement and awareness with the community—(N/A)

TECHNOLOGY

Routine maintenance of the PRISMS website and contribution of ideas to enhance the various tools PRISMS uses for communications, board governance, fundraising and more—(2 people)

REGIONAL REPRESENTATIVE

Serve families in a particular region of the world by providing support, PRISMS resources, and opportunities for engagement in local settings—(N/A)

CONFERENCE

Exhibitors: Identify and outreach to potential exhibitors for the 2018 conference—(4-6 people)

Photography: Attend the conference and provide professional quality photograph—(1 person)

RESEARCH

Identify articles and ongoing research related to SMS around the world and prepare announcements for the PRISMS community via the website—(2-4 people)

EDUCATION

Translation: Review PRISMS website of information and resources and translate info—(N/A)

Articles: Conduct regular searches for news articles related to SMS—(4-6 people)

Connecting With People 'Who Just Get It'

By Dennis Dillon

A chance post on Facebook led to a rewarding meeting between two SMS families this summer.

When Michele LeMasney's daughter, Kendall, was diagnosed with Smith-Magenis Syndrome last December, her geneticist said he had seen only one other similar case. New to the SMS world and hungry for information, Michele and her husband, Michael, asked the doctor if he could put them in touch with the other SMS family.

In the meantime, Michele learned about PRISMS and its Facebook group, so she posted a message about Kendall. A day later, she received a response from Margie Marshall, whose daughter, Kaley, has SMS. Upon further conversation, the two moms realized their daughters had been diagnosed by the same doctor. More coincidentally, they learned they were close geographically.

After several phone conversations, the LeMasneys invited the Marshalls to join them in June at a "Hooked on Fishing" event in Gloucester Township (Camden County, NJ), where the LeMasneys live. The Marshalls, who live in Philadelphia, just across the Walt Whitman Bridge, made the half-hour drive to Gloucester.

"We had the best time," Michele says, recounting the meeting. "It was so special just to see the girls together."

Although Kendall, 9, and Kaley, 13, didn't seem particularly interested in fishing, they bonded over their fancy for playing with the worms. The families spent four hours together.

"It was really awesome to be in the company of another parent who just gets it," Michele says. "Just being around other people who totally understand that (SMS) experience."

Although the Marshalls attended PRISMS' last two "Building Bridges of Hope" Conferences in St. Louis, this was the first time they interacted at length with another SMS family.

"It's definitely cool to be around other people that get it," Margie says. "You don't feel like you're being judged. It was very peaceful."

The two families enjoyed each other's company so much that they decided to get together again at a swim meet in Cloucester Township in late July. And now that they have found PRISMS, the LeMasneys can't wait to join the Marshalls and other PRISMS families at the 10th Conference next summer in Pittsburgh.

"One of the things that I have loved about PRISMS is that the community is so welcoming," Michele says. "From the beginning, there was just total acceptance and total embracement from everybody."

PRISMS 9TH SMITH-MAGENIS SYNDROME RESEARCH SYMPOSIUM

By Emily Fields

On May 18-19, 2017, PRISMS hosted the 9th SMS Research Symposium in Houston, TX. This event is the only event of its kind focused on current research related to Smith-Magenis Syndrome.

The symposium attracted more than 40 professionals from across the country and around the world to participate in this multi-day research event.

By attending the 9th SMS Research Symposium, participants were part of an event that:

- Created open communication of early, unpublished scientific data, accelerating the pace of research
- Furthered research by building productive collaborations - including cross-disciplinary dialogue, partnerships, integration of researchers new to SMS but with interest in specific facets of the syndrome
- Provided educational opportunities for junior researchers to acknowledge Smith-Magenis Syndrome and the array of research potential in the field
- Captured information on current and active research initiatives related to Smith-Magenis Syndrome for public awareness and education

PRISMS is committed to providing information to the SMS community on the latest research findings and advancements. Please visit our website to access summaries of research presented at the 9th SMS Research Symposium: http://www.prisms.org/research/2017-research-symposium.

In 2017, PRISMS has made a commitment of more than $100,000 towards advancing SMS research. We believe research leads to answers. Join us in our fight to learn more about SMS by making a contribution to support SMS research efforts: http://www.prisms.org/how-to-help/make-a-donation.

What Research Means to My Family

By Tina McGrevy

For the SMS Research Symposium, I was asked to speak to the attendees about what research means to our family. A large topic for a short speech, I hope that I was able to hit on the most important impacts the PRISMS Professional Advisory Board and worldwide SMS researchers have made in our lives.

1. Research Validates Our Struggles. The strangest and most amazing part about speaking to SMS researchers is that we do not have to explain Garrett, our 18-year-old SMS son. I can speak to PAB members and other researchers who already just "get" SMS. The articles and publications these professionals have developed over the years put the most difficult struggles of SMS in a form that I can share with Garrett's doctors, teachers and other specialists.

2. Research Changes Our Lives. There are countless examples of how SMS research has helped our family, but we have been personally involved in the Vanda Pharmaceuticals sleep study. Garrett has been taking the drug, Hetlioz, for more than a year, and we have experienced vast improvements to his sleep cycle. The most significant change is that his afternoon meltdowns have lessened, and I truly believe that is due to him sleeping more soundly during the night. My husband and I have all our fingers and toes crossed that this drug will be approved after the study is completed.

3. Research Justifies Nap Time in the IEP. Speaking of sleep studies, Garrett was enrolled about 10 years ago in the sleep studies at NIH. As part of this study, he wore an "Actiwatch" (the grandfather of the Fit Bit) to measure his level of activity. At the same time, we were having difficulties with the school understanding that Garrett needed down time in the afternoon. It was such a relief to bring the printout of his consistent "low activity" during the afternoon hours and have documented proof that he needed space and quiet time. His IEP was changed to reflect this.

4. Research Provides Us With a Guide. *On the Road to Success with SMS: A Smith-Magenis Guidebook for Schools* by PAB members Brenda Finucane and Barbara Haas-Givler was a lifeline for our son's high school years. So many times, when I try to explain what works best for Garrett, I hear my words and it just sounds overbearing. "Don't say 'no', say 'we'll see' instead." Or "If Garrett learns about an upcoming event, he will obsess about it and be unable to attend." These kinds of topics are addressed in the guidebook, along with reasons that might be upsetting to Garrett and possible strategies to cope with these behaviors. Most important, those words come from two trained professionals who have worked with other students such as Garrett. These words do not come from his sleep-deprived, coffee-overdosed and, maybe, just a little bit over protective mother.

5. Research Changes Our Perception. Finally, research changes the way I think of Garrett. I try to empathize how difficult his delays must be for him, but I tend to get caught up in how hard the extra laundry is for me. However, one session at a PRISMS conference completely changed how I viewed Garrett's struggles. A speech about the SMS mice described the reactions the mice had when startled. When researchers tapped on the glass of the cages or flipped the lights on in the lab, the SMS mice had seizures where they froze and gazed upwards. It struck me at how similar that was to Garrett's reaction to loud noises. Although he doesn't have seizures, Garrett does scream, flap his arms or reach out to strike others. It is hard to be sympathetic to that response, but knowing—really knowing, not just guessing—that these reactions are genetically driven completely changed how I react to those outbursts. And it changed how I think about my son in those hardest moments of SMS.

Research has not just improved Garrett's life. It also has made me a better mother.

PRISMS RESEARCH SYMPOSIUM
“A Parent’s Perspective”

By Brandon Daniel

> “What I did not know was how much I would personally gain from the experience.”

I recently had the opportunity to attend my first SMS Research Symposium, May 17-18, in Houston, TX. My initial reason for attending was to show support for the Professional Advisory Board and the other researchers involved in researching the different issues impacting SMS individuals.

What I did not know was how much I would personally gain from the experience.

The sessions provided a unique opportunity to get to know the researchers on a personal level and understand their challenges in the field of research. The researchers also had many questions for me about my family and son with SMS. I believe it was important for me to relate a parent’s perspective to them.

There were several excellent presentations reviewed during the symposium. While I knew there was ongoing research, it was encouraging to get an update on several research projects that I did not know about. I was particularly excited about some of the ongoing and soon to be started gene therapy studies.

I left the symposium with several key emotions/thoughts. I was thankful. Thankful for the researchers and their efforts, thankful for PRISMS supporting research and, specifically, the symposium. Thankful for the parents and families who dedicate their time and resources to continue these studies.

I was optimistic. Optimistic about what the future of research holds for our families. There are many great studies ongoing.

Finally, I was motivated. Motivated to continue to support PRISMS and the researchers who are working tirelessly for our families. Research Matters!

Thankful!
Optimistic!
Motivated!

SMS Research Overview

By Dianne Samad and Sarah Elsea

A UNIFIED AND COMPREHENSIVE PLAN FOR ADVANCING SMS RESEARCH

OVERVIEW

At the 2016 SMS research conference at Baylor College of Medicine, a scientific planning session was led by Drs. Elsea and Alaimo to establish a more unified and comprehensive plan for advancing SMS research. From this session, it was determined funding is needed across three main categories: Clinical Care/ Management, Basic Research and Clinical Trials. Each category was further expanded into high and low priority projects for the current year based on feedback from the scientific community in attendance. A brief description of each study is below:

CLINICAL CARE/MANAGEMENT

1. PATIENT REGISTRY

A patient registry would significantly enhance the organization system for collecting uniform data on SMS patients ranging from clinical, behavioral, and patient experiences. The patient registry's chief purpose would be to centralize and standardize information for all SMS patients. This would enable a distinguished focus on health information. The utility of a patient registry is multifold. First, it is required for the unbiased identification of participants for research studies and clinical trials. Second, it will provide the framework for collaboration between researchers. Lastly, it will provide a tremendous wealth of knowledge toward providing ongoing data for development of standards of care. In addition, such a database will prove great utility for the establishment of a SMS Clinic Network (see point 2 below).

2017 update: *SMS Patient Registry is in the process of development, with goals to go live in June 2017. The collaboration and support of the PAB and the PRISMS BOD, along with significant efforts from Dianne Samad, have made this possible.*

2. SMS CLINIC NETWORK

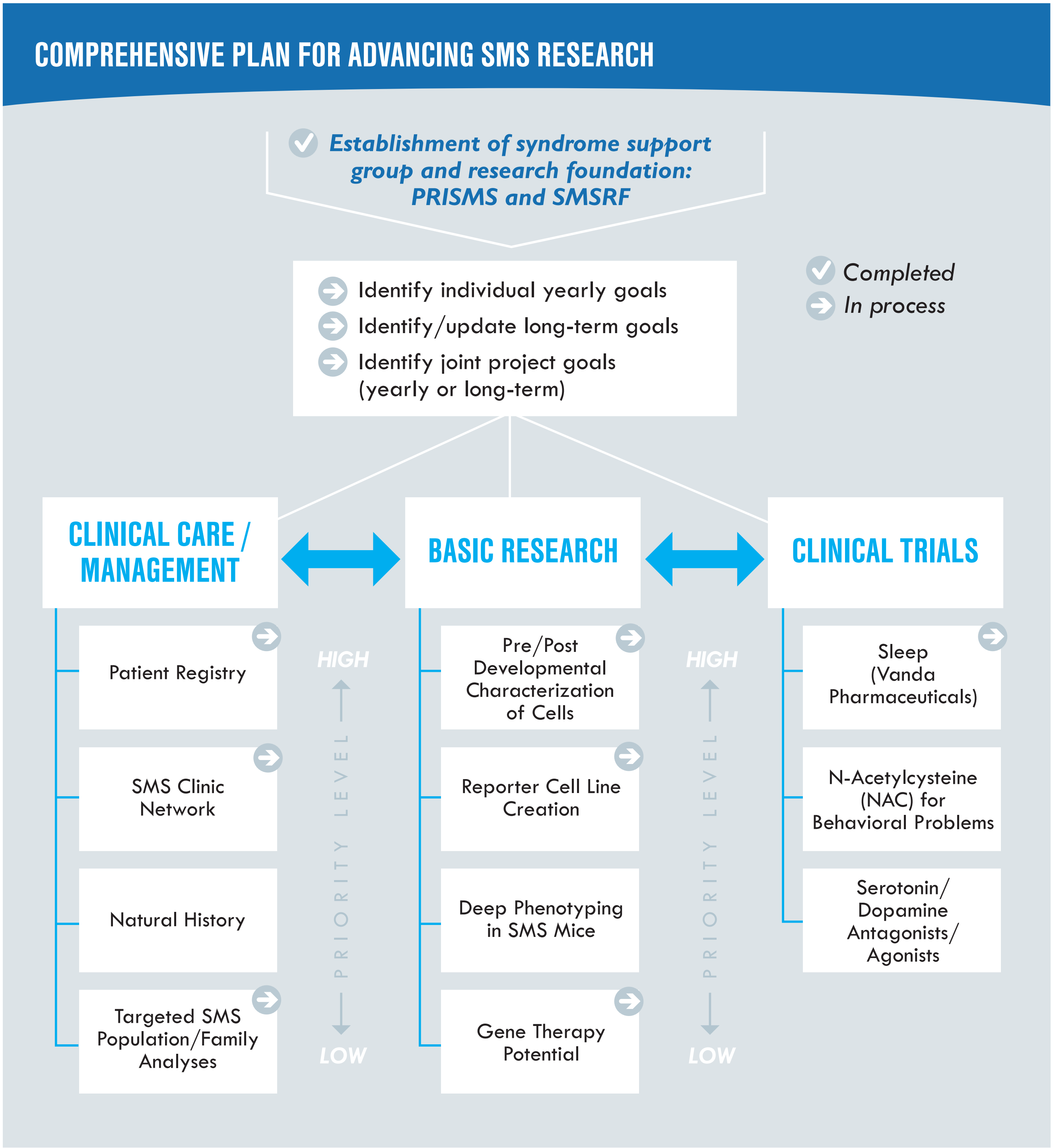
A variety of clinical networks for neurodevelopmental disorders have been established across the country. The goal of this endeavor is to provide better monitoring, care, management and treatment from clinicians dedicated specifically to the disorder. In addition, clinical networks serve as the optimal way to continue to modify current standards of care equally across a population. Lastly, establishing a multisite SMS clinic will also provide the opportunity to enroll patients in any research studies and provide the platform for some clinical trials.

2017 update: *Discussions have begun toward the development of a clinic and provider network across the US with the following goals:*

- *Identify and select the best measures to collect common data on enrolled patients.*
- *Submit/transfer data to the SMS Patient Registry.*

3. NATURAL HISTORY

Data on the natural history of SMS is lacking. A study designed to assess such information is required to understand the needs of individuals with SMS throughout their lives. This task should be relatively easy if the above studies (Patient Registry and SMS Clinic Network) are achieved, largely because they provide the mechanisms to handle the nature of the study. In addition,



COMPREHENSIVE PLAN FOR ADVANCING SMS RESEARCH

✓ ***Establishment of syndrome support group and research foundation: PRISMS and SMSRF***

- ➔ Identify individual yearly goals
- ➔ Identify/update long-term goals
- ➔ Identify joint project goals (yearly or long-term)

✓ *Completed*
➔ *In process*

CLINICAL CARE / MANAGEMENT

- Patient Registry ➔
- SMS Clinic Network ➔
- Natural History
- Targeted SMS Population/Family Analyses ➔

BASIC RESEARCH

- Pre/Post Developmental Characterization of Cells ➔
- Reporter Cell Line Creation ➔
- Deep Phenotyping in SMS Mice
- Gene Therapy Potential ➔

CLINICAL TRIALS

- Sleep (Vanda Pharmaceuticals) ➔
- N-Acetylcysteine (NAC) for Behavioral Problems
- Serotonin/Dopamine Antagonists/Agonists

the NIH has completed some natural history studies. The data gathered in the NIH study could easily form the basis of this goal; however, support is needed to analyze the information and incorporate into a patient registry. Data such as those gathered in a large study would be important to publish so that the entire medical community can benefit from this knowledge.

2017 update: *The SMS Patient Registry and the SMS Clinic Network will facilitate these goals, but this work has not yet fully begun. Support is still needed to curate NIH data to contribute to this process. These data could potentially be uploaded into the Patient Registry for those individuals enrolled at both NIH and the Registry.*

4. TARGETED SMS POPULATION ANALYSIS/ SOCIAL AND FAMILY CONSIDERATIONS AND NEEDS

SMS clinical features manifest throughout life. However, while some of those features have been identified, the developmental period when they become problematic remains unclear. With the aid of the above studies, identifying these items will enable a more targeted approach to future treatments for SMS patients.

Caregivers and siblings have many concerns for the individual in their family with special needs, including high concern anxiety and depression, for caregivers to address many of the concerns for the aging adult with this disorder.

2017 update: *Ongoing studies at Geisinger are attempting to better understand the adaptive and maladaptive coping mechanisms employed by siblings of individuals with SMS and their associated mood and behavioral concerns with the ultimate goal being the development of interventions aimed at developing life-long adaptive coping strategies to reduce risks of mental health concerns. Other studies are looking into associations between parents' behavioral and mental functioning and neurodevelopmental outcomes in their children, with the overall goal being the customization of interventions by identification of a child's main area of behavioral and mental weakness. Support for ongoing and additional studies is needed.*

BASIC RESEARCH

1. PRE/POST DEVELOPMENTAL CHARACTERIZATION OF CELLS

Cellular phenotypes are currently understudied in SMS. We propose to look at the requirements of RAI1 both pre- and post-developmentally and its role in basal cellular function. This task would encompass the analysis of induced pluripotent stem cells, neural progenitor cells, fibroblasts, lymphoblasts, and in vitro models which include the creation of cells using CRISPR technology across tissue types (neurons, retinal, musculature, etc.). Identifying cellular phenotypes that are testable will enable future studies aimed at phenotype correction either though gene therapy, drug treatments, or other methods.

2017 update: *Additional iPSCs have been generated from cells in the SMS Coriell Biobank. These cells are in need of characterization for cellular phenotypes in order to more fully understand early developmental differences between SMS and typical stem cells and neural progenitor cells. Funding is needed for these analyses.*

- *Analysis of mitochondrial phenotypes in SMS fibroblasts is ongoing in the Elsea Lab.*

2. REPORTER CELL LINE CREATION

One potential avenue of treatment for SMS is to return RAI1 expression to normal levels. However, the components that directly regulate RAI1 expression are unknown. This study would begin the process of building a tool that will enable dissecting RAI1 gene expression regulation. The creation of such a tool would provide a platform for future studies, including a drug screen.

2017 update: *A reporter cell line has been generated in the Elsea lab, but has yet to be fully characterized. Challenges include the low level of normal expression of RAI1, so further assessment is required.*

3. DEEP PHENOTYPING IN SMS MICE

Drugs (or molecules) identified in reporter cell line studies will likely need to be assessed for efficacy and validated in a mouse model. The current mouse models for SMS are poor breeders and have subtle phenotypes (with the exception of age-related obesity), and as such, they are not ideal for analysis. Out crossing these mice into different backgrounds or creating new models using CRISPR in different backgrounds may be helpful toward development of a mouse that can be utilized for targeted therapies, such as drug studies or gene therapy.

2017 update: *A study was published by Dr. Luo's group on a set of SMS mice that have significant potential for analysis and utilization in therapeutic studies.*

4. GENE THERAPY

Increasing the expression of RAI1 through gene therapy is one potential therapeutic approach. Since SMS is a developmental disorder, we do not know if increasing RAI1 expression post-developmentally will be successful in preventing or altering phenotypes or improving outcomes.

2017 update: *The analysis of RAI1 vectors is ongoing in the Elsea lab in collaboration with Genzyme and supported by the SMSRF.*

CLINICAL TRIALS

1. SLEEP

Vanda Pharmaceuticals is testing the utility of tasimelteon, an oral compound used in circadian regulation for sleep problems in SMS.

2017 update: *This study is ongoing. Enrollment of adults with SMS has been challenging. Pediatric patients will start enrollment in the coming year. PRISMS could play a more active role in advertising to increase enrollment.*

2. N-ACETYLCYSTEINE (NAC) ADMINISTRATION FOR BEHAVIORAL PROBLEMS

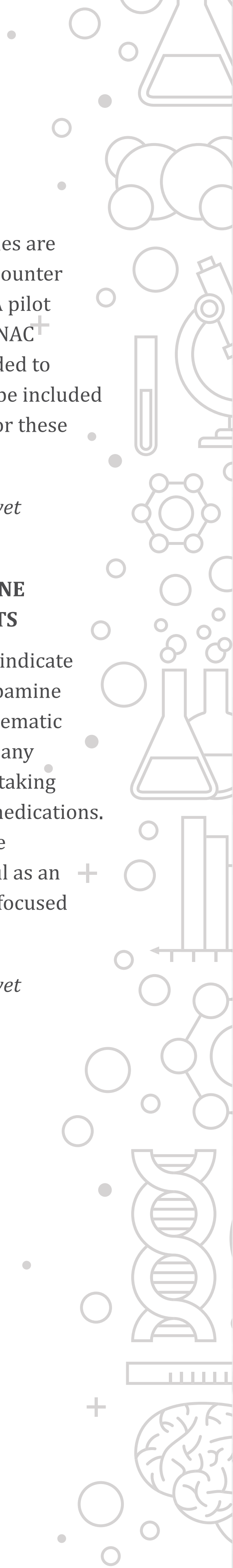
NAC is an FDA approved drug used primarily for acetaminophen toxicity. Off-label uses include behavioral modulation for anxiety related behaviors such as skin picking, hair pull, and stereotypic behaviors. Preliminary data suggest SMS individuals have alterations in the NAC utilization pathway and therefore administering the drug may correct this deficiency. Furthermore, some families are currently using over the counter NAC with some success. A pilot trial assessing the use of NAC in SMS individuals is needed to determine if NAC should be included in the standards of care for these individuals.

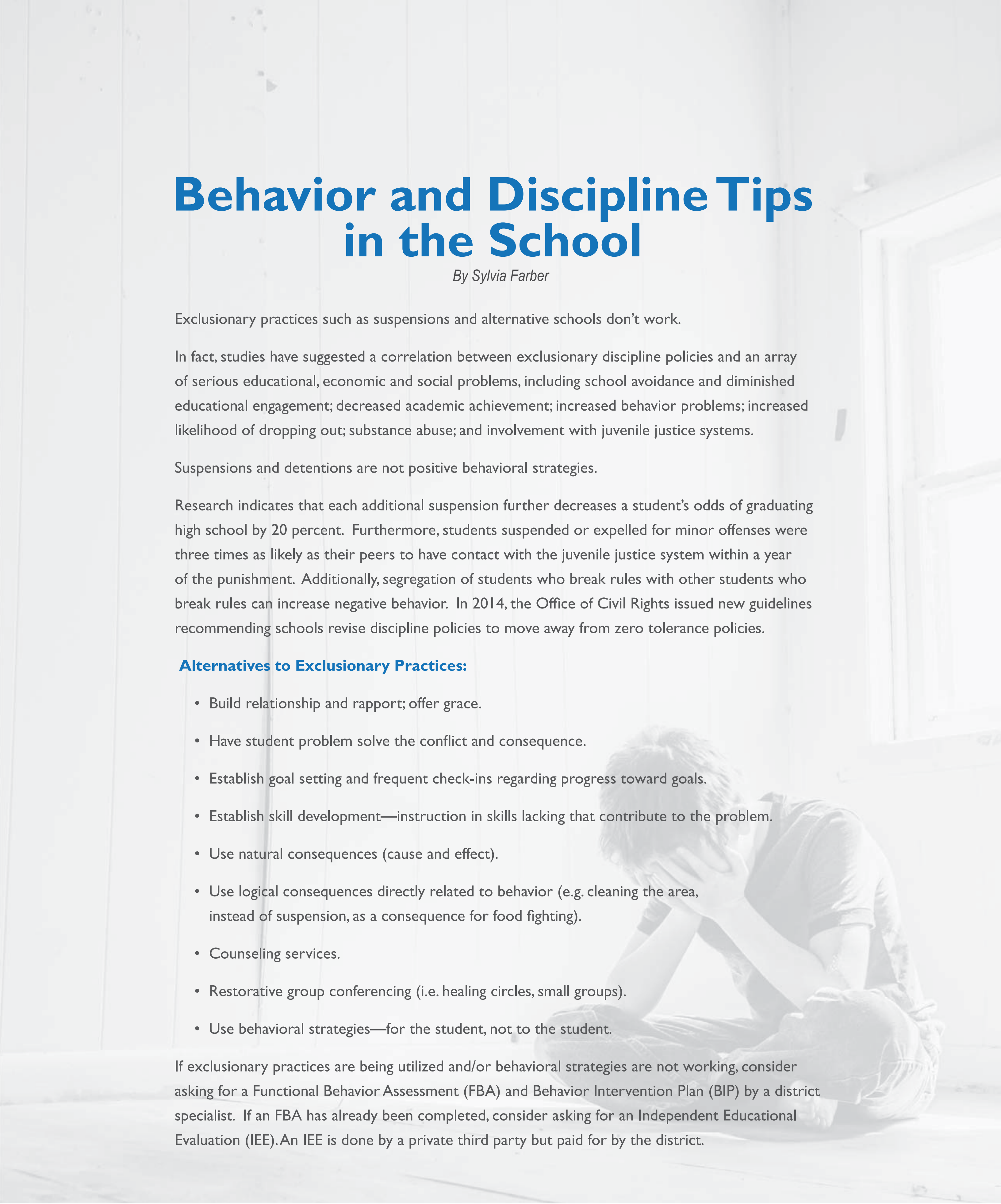
2017 update: *Study not yet started.*

3. SEROTONIN/DOPAMINE ANTAGONISTS/AGONISTS

Published mouse studies indicate altered serotonin and dopamine metabolism may be problematic for the Rai1+/- mouse. Many individuals with SMS are taking SSRIs and other related medications. Gathering data from these individuals may be helpful as an initial study to support a focused clinical trial.

2017 update: *Study not yet started.*





Behavior and Discipline Tips in the School

By Sylvia Farber

Exclusionary practices such as suspensions and alternative schools don't work.

In fact, studies have suggested a correlation between exclusionary discipline policies and an array of serious educational, economic and social problems, including school avoidance and diminished educational engagement; decreased academic achievement; increased behavior problems; increased likelihood of dropping out; substance abuse; and involvement with juvenile justice systems.

Suspensions and detentions are not positive behavioral strategies.

Research indicates that each additional suspension further decreases a student's odds of graduating high school by 20 percent. Furthermore, students suspended or expelled for minor offenses were three times as likely as their peers to have contact with the juvenile justice system within a year of the punishment. Additionally, segregation of students who break rules with other students who break rules can increase negative behavior. In 2014, the Office of Civil Rights issued new guidelines recommending schools revise discipline policies to move away from zero tolerance policies.

Alternatives to Exclusionary Practices:

- Build relationship and rapport; offer grace.
- Have student problem solve the conflict and consequence.
- Establish goal setting and frequent check-ins regarding progress toward goals.
- Establish skill development—instruction in skills lacking that contribute to the problem.
- Use natural consequences (cause and effect).
- Use logical consequences directly related to behavior (e.g. cleaning the area, instead of suspension, as a consequence for food fighting).
- Counseling services.
- Restorative group conferencing (i.e. healing circles, small groups).
- Use behavioral strategies—for the student, not to the student.

If exclusionary practices are being utilized and/or behavioral strategies are not working, consider asking for a Functional Behavior Assessment (FBA) and Behavior Intervention Plan (BIP) by a district specialist. If an FBA has already been completed, consider asking for an Independent Educational Evaluation (IEE). An IEE is done by a private third party but paid for by the district.

CELEBRATING SMS GRADUATES

Every May, SMSers of all ages move forward in education, having accomplished major milestones. Below are just a few of our SMS graduates from 2017!

PRISMS sends huge congratulations to all of our SMSers as they continue to achieve and grow.

Sierra Smith
High School Graduate

Calli Robbins
High School Graduate

Ash Ledingham
High School Graduate

Garrett McGrevy
High School Graduate

Makayla Richard
5th Grade Graduate

Natalie Stephanouk
Kindergarten Graduate

Super SMSers

By Dennis Dillon

Spectrum is proud to recognize the following SMSers for their accomplishments.

Sonja Reiner

Sonja Reiner, 40, of El-Cajon, CA. To celebrate her 40th birthday, Sonja flew cross country—unaccompanied—from San Diego to Boston to visit her aunt. Her flight was delayed twice (passengers had to deplane the second time), but Sonja bravely persevered and completed the 3,000-mile, non-stop flight that took 5 hours 40 minutes. Sonja lived on the east coast when she was younger, and making a return visit had been on her bucket list.

Mackenzie Mazza, 36, of Lake George, NY. For the 13th year in a row, Mackenzie attended the annual Elvis Presley Festival in her hometown. Accompanied by her father, Tom, Mackenzie spent an entire day watching myriad Elvis impersonators show their stuff.

Carson Conley, 10, of Middletown, OH. For the fifth year in a row, Carson participated in the Middletown City Schools Special Olympics, receiving medals for his performances in the 50- and 100-meter dashes and the softball throw.

Lincoln Craig, 10, of Cincinnati. By watching piano tutorials on YouTube, Lincoln taught himself to play several songs, including “Ode to Joy”, the Tetris theme song, and the Rolling Stones’ “Paint it Black.”

Aaliyah Roe, 13, of Salesville, O. Aaliyah recently began participating in a horse therapy program called “Gifted Gaits.” It is a church-oriented program that includes horse riding, horse grooming and Bible study.

Benjamin Berger, 11, of Fairfax, VA. Ben participated in his first band concert at Bonnie Brae Elementary School. He performed twice, once for the students and once for parents. A member of the percussion section, Ben played the cymbals, xylophone and triangle.

Jacqui Huston, 26, Cape Girardeau, MO. Jacqui fished for walleye with her parents on Lake Poshkokogan in northern Ontario, Canada. She caught some fish herself but had more fun holding the ones her mom and dad caught, taking them off the hook and releasing them.

If you have an SMSer who deserves recognition for his or her achievement, email ddillon923@gmail.com.

10th International SMS Conference

Honoring the Past, Treasuring the Present, Shaping the Future
Pittsburgh, PA | July 19-21, 2018

Don't forget to mark your calendars for PRISMS 10th International SMS Conference!

We'll be celebrating 25 years of PRISMS service to the SMS community!

The 2018 PRISMS International Conference is being developed to educate and share information about SMS while providing opportunities for engagement and community among SMS families and professionals.

The goals of the conference include:

- To understand the medical, social, developmental and behavioral aspects of SMS.
- To gain knowledge about the most recent advances in diagnosis, management and potential benefits to persons with SMS.
- To develop intervention strategies, treatment and management plans for persons with SMS.
- To recognize the psychosocial aspects impacting SMS families and the role of PRISMS as a network.
- To learn about SMS, past, present and future.
- And, most importantly, to share information and tips with other families.

The 2018 Conference Committee is hard at work planning for PRISMS 10th International Smith-Magenis Syndrome Conference event. We are looking for your input! Email us at conference2018@prisms.org to share with us your ideas for speakers, session topics, and ways to make this our best conference yet.

HONORING THE PAST | TREASURING THE PRESENT | SHAPING THE FUTURE
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10TH INTERNATIONAL
CONFERENCE
PITTSBURGH 2018

The 2018 Conference Committee, with the support of PRISMS Professional Advisory Board, will take into consideration all ideas and suggestions prior to making final decisions, as our goal is to put together a meaningful conference that supports you and our PRISMS community.

More information about the conference can be found at http://www.prisms.org/2018-conference/general-information.

SPONSORS AND EXHIBITORS

The PRISMS conferences can cost in excess of $200,000 to produce as we offer quality sessions led by renowned experts in SMS, disabilities, rare conditions and more as well as networking time and activities for SMS families over the course of three-days.

We are actively looking for sponsors and exhibitors for our 10th International SMS Conference to help us in supporting these efforts. If you have a suggestion for a company, individual, organization, product, or service that you think would be a good match for us in supporting the SMS community, please share with us at conference2018@prisms.org.

You can learn more about our Sponsorship and Exhibitor packages here: http://www.prisms.org/2018-conference/become-a-sponsor-or-exhibitor.

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Parents and Researchers Interested
in Smith-Magenis Syndrome

EDUCATION | AWARENESS | RESEARCH
prisms.org

FIND US ON SOCIAL MEDIA

Host a fundraiser or awareness event in your area

Contact info@prisms.org for support and ideas to make your event a success.

Join the PRISMS community by becoming a member for 2017

Learn more about membership by visiting our website at www.prisms.org.

Make a donation

Support PRISMS mission to increase awareness, education, and research for the SMS community by visiting our website and making a donation today at www.prisms.org.

Share your story with us

We want to hear from you. Reach out to PRISMS Executive Director at efields@prisms.org.

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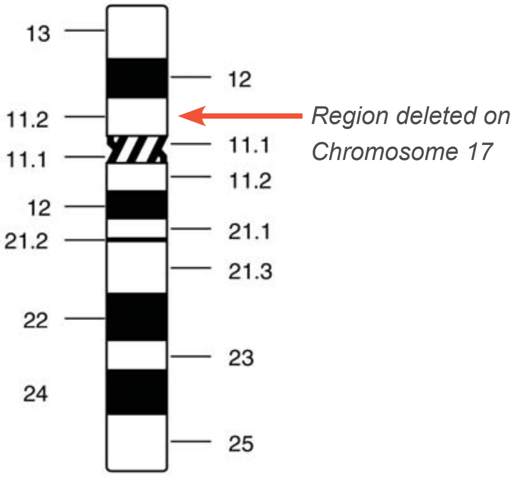
What is Smith-Magenis Syndrome?

Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2.

The first group of children with SMS was described in the 1980s by Ann C.M. Smith, M.A., a genetic counselor, and Ellen Magenis, M.D., a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 15,000 births. SMS is under-diagnosed, but as awareness of it increases, the number of people identified grows every year.



VOLUNTEER OPPORTUNITIES

PRISMS is always looking for helping hands from the community to serve as members of one of our various committees, assist in a program, or coordinate an event. Interested in sharing your time and talents with the SMS community? Contact us at info@prisms.org.

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Editor in Chief: Dennis Dillon editor@prisms.org
Newsletter Committee Member: Pat Boschetto