

Navigating the Affordable Care Act

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The Affordable Care Act., or Obamacare, as it is now commonly known, went into effect in 2010 and was affirmed by the US Supreme Court in 2012, despite the 42 times the House Republicans tried to repeal it.

It will have the most drastic impact on 48 million Americans who don't or haven't been able to get insurance.

By 2014, everyone, with a few exceptions, has to have insurance or face a penalty.

What do you need to do?

If you already have health insurance, Medicare or Medicaid, you don't need to do anything. If you don't, you need to go to www.healthcare.gov and follow the directions. You'll end up getting various choices with prices adjusted for your age and income, typically separated into platinum, gold, silver and bronze options. If your income falls between 100 and 400% of the poverty line between \$23,000 - \$94,200 for a family of four you'll get a subsidy so your actual cost will be anywhere from 2 - 95% of your gross pay. A 26-year-old, without employer, will be covered by parent's insurance.

One unfortunate quirk: If you make less than the poverty level and live in a state that refused to expand Medicaid, you are pretty much out of luck. Because of an infuriating shortcoming in the law, you must pay full price on the exchange. Go to www.localhelp.healthcare.gov to find help in your area. Policy kicks in January 2014.

Free vaccines for kids, cheaper drugs for the elderly and many other benefits of President Barack Obama's healthcare law are already out there. More are coming, like a guaranteed right to buy health insurance even for patients with serious medical troubles. Many businesses and wealthy taxpayers, however, will see their costs go up.

The ruling affects virtually every American. Obama's healthcare law tells almost everyone they must be insured and makes sure that coverage will be available to them even if they are

already ill or need hugely expensive care. It helps the poor and many middle-class people afford the cost. And it requires insurers to provide certain basic benefits, like preventive care without co-pays from the patient.

The Supreme Court upheld almost all of the law, including the most disputed part: the requirement that virtually all Americans have health insurance or pay a penalty. The court said the penalty is essentially a tax, and that is why the government has the power to impose it.

The ruling somewhat limits the plan to expand the Medicaid insurance program for the poor, a joint effort of the federal government and states. It says the government may not withhold a states' entire Medicaid allotment if it doesn't participate in the expansion..

So far, the law has eliminated co-payments for preventive care. Insurers can't deny coverage to children. Limits to how much policies will pay out to each person over a lifetime are eliminated. And millions of older people already are saving hundreds of dollars through improved Medicare prescription benefits.

By 2016, the Congressional Budget Office has estimated about four million people will pay the penalty for not being insured. They would pay \$695 for each uninsured adult, or 2.5% of family income up to \$12,500 per year.



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President's Message



As I write this, we are rolling out an exciting new Regional Representative program. In the past, we've had a program called "Parent-to-Parent" to connect parents of newly diagnosed kids to other parents. Our Regional Rep program builds on the success of Parent-to-Parent. The new program is intended to get more folks involved and connected with each other in the PRISMS community. Each region of the US and many foreign countries will have a representative listed on our website. The person listed will have a PRISMS membership listing for their region and can be contacted by anyone who needs help. In addition, we hope that they will be able to facilitate regional social gatherings such as picnics. If you need to talk to someone, please check out our website to find out the PRISMS Regional Representative nearest you!

It is also important to note that the PRISMS Board has voted to establish an endowment to help support our organization in the future. We want to ensure that PRISMS will be around for many years to continue our mission of helping families and promoting research. Some of our members are very committed to raising funds to support PRISMS, and you will read an article written by a sibling who is doing just that. We need your help, too. A good way to get started helping us with fundraising is to donate an item to the silent auction that will be held during the PRISMS conference this summer. Donate something, and bring your dollars to buy, too!

I hope you are making your plans to come to the 2014 International Conference. My family's first conference was life-changing. You will benefit from the workshops and opportunities to hear about the research, but most people say meeting other children with SMS and their families is the best part.

In 2013, we lost a precious boy with SMS, David Seely. David made a big impact on the world in his very few years here and PRISMS is happy to be able to honor his memory. Don't miss reading his story.

And finally, don't miss the SuperKid article in this issue. SuperKid is usually written by a parent, but this time the author is a person who has SMS.

As always, the PRISMS board is here to serve you! I hope you enjoy this edition of Spectrum.

Best regards,

Randy, father to Laura, age 29, with SMS

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Do you love social media? Check out the PRISMS Facebook page and Twitter account. Our numbers are growing quickly. Our page is being organized by volunteers, David and Denise Smith. Facebook is a great way for families and others to share information and learn about Smith-Magenis Syndrome. Search for "PRISMS/Smith-Magenis" and become a "friend."



By following PRISMS twitter account at: https://twitter.com/PRISMS_SMS, you can learn about upcoming events, programs and new SMS research and information.

PRISMS Welcomes New PAB Members

PRISMS is proud to welcome two outstanding experts to our Professional Advisory Board. Dr. Jane Charles and Dr. Rebecca Foster have joined the PAB this year and will serve three-year terms. PRISMS welcomes new PAB members.

Our Professional Advisory Board is charged with the task of overseeing all medical, therapeutic, educational and research information that is provided to our families. This charge is in keeping with a major PRISMS goal “to support and promote research into the causes, management, and treatment of Smith-Magenis Syndrome.” Members of the PAB are professionally accomplished in a field of endeavor relevant to SMS, as documented from reputation, publication, and/or direct experience and knowledge of Smith-Magenis Syndrome.

The PAB consults with families, other researchers, clinicians and physicians, and is a resource for specific questions and concerns that are presented by families and professionals. The PAB is involved with updating the “Medical Management Guidelines for SMS,” and GeneReviews. (GeneReviews is an online database of peer-reviewed articles that describe SMS and other diseases). The PAB also reviews all requests for research projects and studies that require participation from our members.

Research requests undergo a stringent IRB (Institutional Review Board) by the PAB and are assessed for their efficacy, relevance, safety and appropriateness for our membership. The PAB wears many hats and volunteers their time serving our community. We are very grateful for their work and study of SMS and their dedication to our families. We hope you will join us in greeting our new Professional Advisory Board members and if you plan on attending the PRISMS conference in July, they will also be in attendance.



Rebecca Foster is a licensed pediatric psychologist and assistant professor of psychology at Winona State University in Winona, MN and Gundersen Health System in La Crosse, WI. Dr. Foster’s research, clinical, and teaching efforts emphasize the promotion of psychosocial

well-being and quality of life among medically complex pediatric populations, examining family adaptation and caregiver well-being within the context of chronic illness and/or neurodevelopmental disorders, and addressing adolescent and young adult health behavior, risk-taking behaviors, and self-efficacy development. Recent work in SMS has focused on identifying and meeting caregiver/parent and typically developing sibling needs, with a concentration on benefit-finding and adaptive coping across the lifespan.



Dr. Jane Charles is a Developmental-Behavioral Pediatrician in the Department of Pediatrics, Division of Developmental-Behavioral Pediatrics at the Medical University of South Carolina in Charleston, SC. Dr. Charles is an active clinician, researcher, and educator. Her areas of

specialization are in the fields of Autism Spectrum Disorders (ASD), intellectual disabilities, and genetic disorders. She provides developmental follow up and medication management for comorbid behavioral disorders for children into adulthood. Dr. Charles has received research funding as the principal investigator, or co-investigator for a variety of grants exploring issues related to developmental disabilities including investigating the prevalence of ASD and Fragile X as part of the CDC’s Autism and Developmental Disabilities Monitoring Network.

**PRISMS 8th INTERNATIONAL
CONFERENCE**

"BUILDING BRIDGES OF HOPE"

**Thursday, July 31st, 2014 through
Sunday, August 3rd, 2014**

**The Hilton St. Louis at the Ballpark, St.
Louis, MO**



8TH INTERNATIONAL CONFERENCE • ST. LOUIS 2014

The PRISMS Conference is quickly approaching and registration has already begun. Families from around the globe will come together for four days of sharing, learning and fellowship. SMS experts, including parents, will be presenting on many venues, including research updates, medical management, education supports, transition to adulthood, sibling workshops and much more. The conference is a time for families and professionals to come together to celebrate our SMS children and explore the next steps together. We hope to see you there!

To register for the conference, please visit the PRISMS website and visit 2014 Conference Information and FAQs. Reduced rates for the conference and hotel are available until July 5, 2014. After July 5th, fees will increase.

<https://ww2.eventrebels.com/er/EventHomePage/CustomPage.jsp?ActivityID=10023&ItemID=38698>

CONFERENCE COSTS

Registration including meals (US dollars) per person:

	Until 7/5/2014	After 7/5/2014
Adult (15+)	\$200	\$250
Child (14 & under)	\$100	\$125
SMS Individual	\$75	\$100
Professional	\$275	\$325
Professional In-Training	\$225	\$275

Five meals and a light reception will be provided: reception Thursday evening, continental breakfast each day (3), lunch Friday and Saturday.

HOTEL

The conference will be held at the *Hilton St. Louis at the Ballpark, St. Louis, MO.*

* Please use the website link below to reserve a room at the PRISMS discounted rate of **\$129.00 single/double**, plus applicable taxes. The discounted rate is available three days before the conference as well as three days after the conference based on availability.

* Make your reservations prior to **July 5, 2014** to receive the discounted rate.

* After **July 5, 2014** the discounted rate may not be available.

* Click on this hotlink or call 1-877-845-7354.

<http://www.hilton.com/en/hi/groups/personalized/S/STLBVHF-PRS-20140725/index.jhtml>

CHILD CARE

This conference is intended for parents and professionals. If you are unable to make local arrangements for childcare, PRISMS is offering childcare through an outside firm, Corporate Kids. Corporate Kids will provide childcare for SMS children and their siblings, between the ages of 4-18 years old. The subsidized price of \$150 per child (for two days) does NOT include the child's conference registration fee of \$75. Childcare will be available on a first come first served basis. Registrations for Corporate Kids must be made prior to **July 5, 2014**. Use the link below to directly register your child with Corporate Kids childcare.

<https://conferencechildcare.com/prisms-conference-2014-kids-camp-registration/>

Special event for our SMS adults (ages 16 and up)

This conference, we are offering The PRISMS Den for our SMS adult attendees, ages 16 and up. The PRISMS Den will take place on Friday, August 1st and Saturday, August 2nd, from 1:00pm – 5:00pm. Corporate Kids will also be providing 1:2 supervision for The PRISMS Den. The Arc of St. Louis will also be participating in The Den and will provide fun, engaging activities as well. The PRISMS Den will be geared towards our adults and include activities such as:

Nintendo Wii/Xbox Video Game Contest

Music Time (instrument play)

Craft Stations

The cost for The PRISMS Den is \$66 for the two days or \$33 per day. You may register for both the childcare and the lounge if your child is between the ages of 16-18, but both fees would apply.

Please use the link below to register for The PRISMS Den.

<https://conferencechildcare.com/prisms-den-2014-registration/>

FINANCIAL ASSISTANCE

In the past, some families in need have received free transportation and partial or full funding from community resources such as social services, local churches, synagogues, Special Education Services, Knights of Columbus (www.kofc.org/), the Shriners (www.shriners.com), Lions Clubs International (www.lionsclubs.org), Salvation Army (www.salvationarmyusa.org), Angel Flight - serving the western US (www.angelflight.org or 1-888-4AN-ANGEL), and National Patient Air Transport - serving the eastern US (www.npath.org).

In addition, a limited amount of financial assistance is available directly from PRISMS. The deadline for financial aid applications is **June 1, 2014**. Please contact financialaid@prisms.org for more information.

Additional Information

Parents!

It's time to send in your photos and video clips for our 2014 PRISMS conference!

We would like to showcase all those bright smiling faces!

If you are interested in sending a video clip we prefer they are in mp4 format but any format will do. We are asking for a 30 second clip and we will use as much of it as possible.

As for Photos, each family can submit two. Please include your child's first name for the slideshow pictures and a first name and title for the video clips, (eg. "Joey at his swimming lessons.").

Send them to: pictures@prisms.org no later than June 30, 2014.

Silent Auction

It is conference time and that means you have another opportunity to help PRISMS. Once again, the popular SILENT AUCTION raises money for OUR organization and you can be a big part of that. Here is what we need from you...



PRISMS Mission Statement:

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS.

1. Talk to your employer and see what kind of items they are willing to donate for the auction. This could be something they produce, something they've received, something they can obtain. Just ask. Do they deal with other businesses that would offer something? Gift certificates, personal items, tickets, etc. Just ask!

2. Do you have a friend that is in some kind of creative business? An artist? Someone who owns a business and would be willing to donate a gift certificate or something electronic or a painting or anything that would raise money for PRISMS?

3. Please let us know what you've obtained or can obtain for the auction so we can put it on our list. Thanks for your help and let's make this a great SILENT AUCTION!

For questions about the Silent Auction or to offer donations or help, please contact the Silent Auction chairperson: silentauction@prisms.org

Transportation

Hilton St. Louis at the Ballpark is 20 minutes from Lambert-St. Louis International Airport (STL). There is not a free shuttle from the airport but, Go Best Express Airport Shuttle offers discounted rates.

How to make reservations:

A special convention rate has been negotiated on PRISMS behalf. Reservations MUST be made online to receive the discounted rate before 11:59pm, July 20th, 2014. Walk-ups will not be eligible for convention rate, and standard rates will apply. Please use the link below to Go Best Express and begin your reservation to reserve a seat. The discounted convention rate of \$18 one way or \$34 round trip per person is offered. Credit cards are required and charged at the time of reservation.

<http://besttransportation.hudsonltd.net/res?USERIDENTRY=PRISMS&LOGON=GO>

If you are planning to drive to the hotel, PRISMS has a discounted rate of \$10/day for self-parking and \$16/day for valet parking.

Hilton St. Louis at the Ballpark Hotel Information

Please use the website link below to reserve a room at the PRISMS discounted rate of \$129.00 single/double, plus applicable taxes. The discounted rate is available three days before the conference as well as three days after the conference based on availability.

* Make your reservations prior to July 5, 2014 to receive the discounted rate.

* After July 5, 2014 the discounted rate may not be available.

* Click on this hotlink or call 1-877-845-7354.

<http://www.hilton.com/en/hi/groups/personalized/S/STLBVHF-PRS-20140725/index.jhtml>

Parent-to-Parent

Did you know that PRISMS sponsors a parent-to-parent program? If you need someone to talk to who REALLY UNDERSTANDS what your life is like, try another SMS parent. You may want to find another parent in your area, or perhaps one who has a child the same age as yours. Tell us what you need. PRISMS keeps a list of parents willing to be contacted. We'll send you addresses and phone numbers, and then you can talk all you want.

Contact:

Mary Beall
Phone: 972-231-0035
mary.beall@tx.rr.com

Important note: PRISMS Parent-to-Parent program will only give out information on parents who have agreed to be contacted. If you would like to be added to the list of contact parents, please email Mary at the above address.

David Seely

My Little Angel

By Beth Seely

David was born on super bowl Sunday -- February 6th, 2005 but I was not able to take him home until he was 34 days old. He had a rough start to life but that did not stop David from beating all expectations. He was not developing like he should so I enrolled him in the Spokane Guild's school at the age of 3 months. It took about 3 weeks to have him evaluated and then start therapy at the school. I later found out that most people had to wait on a list for several months, but not David. Even at that young age he was finding ways to the front of the line. He would be the first to tell you he was the line leader.

He was diagnosed with Smith-Magenis Syndrome (SMS) when he was 7 months old. I had never heard of this syndrome and had no idea what to expect. David had extremely low muscle tone. In fact, he was not able to hold his head up until about 6 months of age and could not sit by himself until he was almost a year old. Knowing this, the doctor was preparing me for the possibility that David would have a hard time walking; in fact he may not walk until he was much older – closer to five-years-old, and even then, he may need to have assisted devices like a walker and braces. Well, no one told David he would have a hard time. He was walking at 20 months. Not only did he walk into the doctor's office, he ran into the



office and into another child's exam room to say hi to the doctor. After I took David out of that child's exam room and into his exam room, the doctor came in and looked at David with a smile on his face and said to me, "I told you David would not be walking until he was about 5—well, I guess I lied".

That is how David responded any time someone tried to place a limitation on him, or have low expectations about what he could or could not do. Anyone who attempted to place such limits on David were quickly put in their place by this smiley boy who never let anything stop him from achieving what he wanted. He always worked hard in his therapies and hated it when the session was over. His therapist can attest to that.

The one person in David's life whom he adored more than anyone or anything in the world was Alyssa, his big sister. In fact the reason David was able to do all the things he could was in a big part because of her. She would spend hours after school playing with him in such a way that helped him develop his muscles stronger. David loved his time with his sister and would do anything for her.

From the time David was a baby he was Alyssa's soccer team's mascot. He often would come to practices and games dressed in his Elmo costume; well, for David it was not so much a costume but a fall coat. He would run up and down the field, kicking at any soccer ball on the side lines and trying to get on the field next to his GAGA, his big sister. As Alyssa and David got older, David was no longer satisfied with the sidelines. So he would join in with his big sister's practices. He loved scrimmaging with them, running lines and shooting goals. Here were all



these big high school kids and David right with them. During the games David took his position right next to Coach Ryan as his little coach – Coach David. He walked up and down the field with Coach Ryan and occasionally run onto the field. I think the other parents enjoyed watching me chase after David up and down and onto the field as much as they enjoyed watching David.

In the spring of 2012 David joined the buddy ball league which is a part of Babe Ruth Baseball program. For the first time David had his own uniform. He loved that uniform. He slept in it for several days straight. He loved having his own team and playing with Coach Larry. During the games he played in, all bases were dirt free; he made sure of that by stopping at each base and cleaning it off. He had to do it. After all, why should the catcher be the only one who got to dust of the bases? At the end of the season when he had his banquet he was so proud to get his own trophy. He held that trophy and just beamed for days. He also received a DVD of pictures from the season which we had to watch at least 15 times the first night. In buddy ball David had found a place where he belonged. And I knew I did not have to worry about his disability—everyone was so accepting of him. David was just David, not a boy with a syndrome.

David also loved school; one of the enjoyable features of SMS is the fact that the kids are incredibly social. So school was a place for socializing and fun in David's book. He did have a rough start in the public schools, but when he started Finch Elementary in 1st grade he was truly home. He loved Finch and his teachers Mrs. Luciani and Mrs. Cook, his very special Mrs. Ryer (his aide) and we can't forget his Miss PattyClark – all one name—Mrs. Harmon and the staff. He would not say I am going to Finch or my school; what he said was, "I am going to My Finch" and it was his Finch. He knew everyone. There was not a name badge he did not grab or a kid he would not hug. Alyssa and I would marvel as we walked him to his class line at the beginning of the day how many older children would say hi to him or stop and give him a hug. We never made it across any street without having to hug the crossing guards. One of his classmates told me one morning that hugging David was mandatory, even if you did not want one you gave him one anyway because it was David.

When David got sick, his charm and smile won over many of the nurses in the ICU; in fact, he asked one of them to marry him. David was such a fighter and true to form he never did what the doctors thought he would. He fought so hard but still smiled, even though I could see he was in pain. He spoke with his eyes so loudly everyone could hear his love and joy for life. He truly is my little super

hero. He faced so much but never gave up. People would ask me how I could handle his illness and the stress it caused. I would just say because David gives me the strength. It was always David being strong and fighting; I was just his number one cheerleader through it all.

David may have only been on this earth for 8 short years, but in that time he touched more people than I can hope to touch in my entire life. His smile would disarm anyone. He only knew a person as a friend. The idea of an enemy did not exist in David's world. As parents, we are supposed to teach our children, but David taught me more than I could have ever taught him. He taught me that whatever life gives you, fight on. He taught me to never let anyone place limitations on you. He taught me how to smile in the face of such pain. But most of all, he taught me to STAND strong in the face of whatever life has in store for you.

One of the lines of the song "If I had Wings" says "what would I leave that will go on forever," I know that David will leave the gift of love. Because each person he touched is a better person for having known him.

I will always love you my little monkey boy, my true super hero, my sweet boy, My David. Thank you for being a great teacher and a wonderful inspiration.



Silent Auction

Hello fellow SMS families! Lynne and Steve Baker, parents of an SMS daughter, are running the Silent Auction (SA) at the upcoming conference and we are really excited to raise more funds for PRISMS.

The last SA in Denver made over \$7,000 that went directly back to PRISMS. These funds are used to offset conference costs for registration, childcare, and other conference expenses. They also fund scholarships that enable people to attend the conference. We all know how powerful it is to have a group like PRISMS to support our efforts as parents of children with SMS, so we want to ask everyone to think about how you will support the SA this year. Can you donate one or two items? Can you come to the conference and bid on some items? Can your employer donate some items?

Items that have done well at past auctions include electronics, DVDs, toys that SMS kids love, coffee blends, and gift cards. If you have something to donate or if you have any questions about the SA, please feel free to contact us via email, text, or phone. Even if you are unable to attend the PRISMS Conference this year, you can still donate by sending an item. There is an SMS family close to St. Louis that is willing to collect donations and bring them to the conference - just contact us for the mailing instructions. Thanks to everyone for your support and we look forward to this year's conference!

If you have questions or items to donate please contact us at: silentauction@prisms.org

A Birthday to Remember

I started writing my birthday party invitations and decided that I did not want to have birthday presents this year. Instead, I wanted to help raise money for kids who have SMS so that more research could be done about this syndrome. The reason I decided to help PRISMS is because Cooper Wagener, my Aunt Janet's son, has SMS. I spent a day with Cooper over the summer and realized that he has many special needs. So, on my party invitation I asked everyone who was invited not to bring any gifts. I asked my friends and their families instead to consider making a donation to help support PRISMS.

On the invitation I included the website for PRISMS so that people could learn more about it. It made me feel so excited that all of my party guests participated and brought money to support SMS. They placed their donations in a box that I created ahead of time and brought to the party. It had a picture of Cooper and me on it. The box said, "Thank you for helping me help kids like Cooper." I counted up my money when I got home and we had raised \$370. I was so happy that I emailed all the people who came to my party to tell them how much money we had raised together and how thankful I was for their contributions. Then, we went to my Aunt Janet's house and we showed her the box and all of the donations inside. She was so touched by everyone's kindness. I hope that the money I raised will help to find a cure for SMS.

By: Karli Oates (Age 10)



Cooper and Karli



Research Opportunity

A very exciting research opportunity is available for our families from Vanda Pharmaceuticals. You will receive more information when you contact Vanda directly. We encourage you to investigate this opportunity and we will keep our families updated about the study.

Representatives from Vanda will also be presenting at the upcoming conference.

A new clinical study is investigating circadian rhythms and sleep disturbances in people with Smith-Magenis Syndrome to guide the development of a possible treatment.

Your child or dependent may qualify if all three criteria are met:

- They have Smith-Magenis Syndrome
- They have sleeping problems
- They live on the East Coast

Qualified individuals will be compensated for their time and effort. Transportation will be provided at no cost.

For more information contact
SMStrials@vandapharma.com or
call toll-free: **844-366-2424**

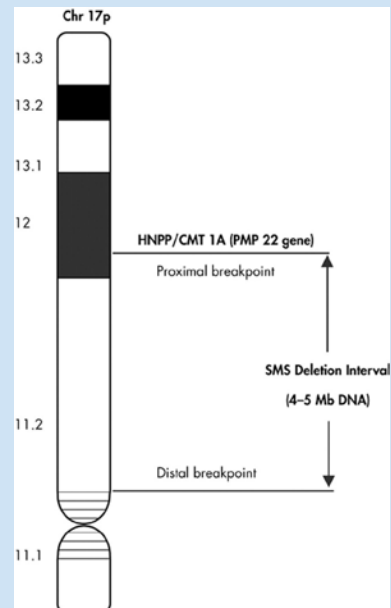
What is Smith-Magenis Syndrome?

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 underdiagnosed, but as awareness of it increases, the number of people identified grows every year.



Volunteers Needed

Volunteers have always had an important place at PRISMS. Our volunteers have supported efforts at conferences, edited articles for Spectrum, raised awareness, held fundraising events, served on the Board and contributed in dozens of other ways. As we continue to support more and more families, we are expanding our volunteer opportunities. We are asking members who would like to support PRISMS to send an email to info@prisms.org.

Percy Huston will coordinate these efforts moving forward. We look forward to hearing from you. **We currently need editors for the *Spectrum* journal. If you are interested please send an email to the address above.**

SMS SuperKid

Erik de Kimpe

My name is Erik de Kimpe. I was born March 23, 1992 in Amersfoort, the Netherlands.

I got my SMS diagnosis when I was eleven-years-old, (the doctors studied me from the day I was born!!). From then on I got the (professional) attention I need so badly.

During my life with my parents and my big sister, Linda, I visited a school for children with special needs, I liked it there, but I had to move on and start a career.

So I moved out from my parents, I wanted to follow in my sisters footsteps; she had already moved out to study in another city. She will be a teacher for children with special needs! She moved to Baarn, a nice town with a big community for “special” people, not too far from my family.

I live together with 4 other boys, and some amazing caregivers. I started a job at a petting zoo next to my new home; they call me the “King of Chicken.” I search for eggs and clean cages for three days, and on Friday I do all kind of chores on the property.

Wednesday and the weekends are my days off — always nice days; my parents often visit me or I go out with them or with one of the caregivers.

During my life I made a lot of friends. They visit me and take me out (movies, restaurants, bars, hotels etc.), and I give them my well-known HUG. Hugging is



far from common in our country; I’m introducing it and everybody loves it.

The things I like best are surprises — it doesn’t have to be a big one — and holidays.

I’ve traveled around Europe and Mexico. I’ve been twice in North America with my family (aunt, uncle, nieces, a nephew, parents and sister) travelling in two RVs. The best holidays ever: all your loved ones around for the whole day. I can recommend that!

I hope you like my story. I end it with a big HUG for all of you.

Do you have an SMS SuperKid? We know what amazing things our kids can accomplish, and those big and small moments of success need to be celebrated for all to see. Please consider sharing your moments with us. If you have questions or need help with the story, please contact the editor at editor@prisms.org.

SPECTRUM, The PRISMS Journal of Smith-Magenis Syndrome is seeking an Editor.

- Are you a capable writer, and want to be connected to the Smith-Magenis community?
- Are you comfortable soliciting articles from a range of professionals?
- Are you able to think creatively about generating and presenting interesting, valuable content?
- Are you highly organized, able to commit up to 10+ hours per month and able to work to tight deadlines?

If you answered "yes, yes, yes, yes"
please consider applying to serve as the SPECTRUM editor!

The *SPECTRUM* editor works with the Board to plan the annual editorial calendar and develop and deliver quarterly editions. The successful candidate will receive support from the Board and previous editors.

To apply, please send to editor@prisms.org a paragraph explaining why you are interested in volunteering and how your strengths/experiences would make you a good candidate. If you wish to talk to someone about this position, please send your contact information to the above email.

Don't feel like you are ready to be an editor but want to contribute? We are also looking for regular writers and persons interested in assisting with the development of the Journal. Please contact us if you have an interest (or ideas!) by emailing editor@prisms.org.

"I really loved producing these publications, and was very proud to see it hit my mailbox. I know that others would find the same sense of accomplishment and giving that I had when I worked on it."



"It was a privilege to work as an editor for Spectrum and with the PRISMS board on this important journal. The greatest tool for parents of SMS children/adults is information and I felt like I played a small role in helping disseminate information that would increase the quality of life for the SMS community."



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